Children's Participation in Paediatric Rehabilitation

An Exploration of Consultation Practices

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Oslo, October 2013

Wenche Bekken

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Chapter 1: Background

Children's participation in paediatric rehabilitation

Many children with disabilities are evaluated and undergo physical examinations on a regular basis. Professionals enter the children's life at a very early age, and the children cooperate with professionals from childhood throughout their adult life. From their relationship with professionals the child learns about his or her impairment and how to live with it in everyday life. The child takes part in encounters with adults where the impairment and disability are assessed, evaluated and discussed. These are encounters that may affect the child's self-perception. Follow-up at the paediatric rehabilitation centre is scheduled once or twice a year, and the evaluations are carried out as a means of supporting the child in everyday life activities.

In the following I will give a presentation of the background for conducting this research project based on research findings on the topic. Although research findings on the topic are presented in the papers, I find it appropriate to give a summary in this chapter.

Participation during consultations

Research concerning the participation of children with disabilities in consultations and their involvement in decision-making processes shows that children's participation varies (Coyne, Hayes and Gallagher 2009; Garth, Murphy and Reddihough 2009; Shilling et al. 2012). Paediatric outpatient and inpatient settings document that children want to be involved in decision-making, but that there is some variation as to how and to what degree they want to participate (Alderson 1993; Beresford and Sloper 2003; Coyne, Hayes and Gallagher 2009 2009; Young et al. 2003). Children are often left out of conversations when parents are present (Cox and Raaum 2008; van Dulmen 1998; van Staa 2011). It is also documented that children like to be visible and included in communication with healthcare professionals, but how they like to occupy this 'visible-ness' varies from child to child and needs to be more fully addressed (Lambert, Glacken and McCarron 2008). Paper 1 investigates a consultation in order to reveal dimensions that affect children's participation. In paper 2, three examples of how they like or dislike the consultations at the paediatric rehabilitation centre are explored.

Listening to and communicating with children

Studies focusing on children's experiences from participation in decision-making highlight the importance of listening and communicating with the children and their parents for successful intervention for children with disabilities (Garth, Murphy and Reddihough 2009;

King et al. 2012; Shilling et al. 2012). Communicating and being informed increases the child's opportunity to be involved in decision-making processes: it makes children feel valued and less anxious, angry or upset by not being involved in decisions (Garth, Murphy and Reddihough 2009; Kelsey, Abelson-Mitchell and Skirton 2007; Shilling et al. 2012; Young et al. 2006; Young et al. 2003). Paper 3 explores professionals' experiences and children's views on children's participation and involvement in decision-making.

Barriers for children's participation in health care

Research literature on children's participation in the healthcare setting has investigated what may act as barriers. A recent review study emphasizes the professionals' attitude and their way of communicating with children, as well as cultural and structural condition (Olli, Vehkakoski and Salanterä 2012). It is documented that professionals' way of acting out their role may give rise to objections from the child (Runeson et al. 2001). How parents involve themselves affects the child's participation (Coyne and Gallagher 2011; Coyne and Harder 2011; Coyne, Hayes and Gallagher 2009; Hallström, Runeson and Elander 2002; Runeson et al. 2001; Runeson et al. 2002), and it has been shown that mothers give the healthcare professionals more information than fathers (Cox et al. 2007). In addition, girls are more involved in conversations during consultations than boys. More involvement in conversations extends the length of the consultation. Age may affect participation, but may not be decisive (Runeson et al. 2002). The three papers address factors that affect children's participation.

Children's participation and professional practice in paediatric rehabilitation

The concept of participation is central and is widely recognized in paediatric rehabilitation and in the disciplines of occupational therapy and physiotherapy (Law 2002; Majnemer et al. 2008). Recent decades have seen an increase in the attention to and research concerning how professionals should measure children's involvement in everyday life activities (Dunst et al. 2002; Law 2002; Orlin et al. 2010). Within paediatric rehabilitation the International Classification of Function, Disability and Health, Children and Youth Version (ICF-Y) is applied as a tool for defining and measuring health and disability, and it provides a policy formulation for health and disability worldwide. The term functioning encompasses all body functioning, activities, and participation. In this classification disability is defined as a result of the relationship between the individual and environmental conditions: impairments, activity limitations or participation restrictions (WHO 2003). In the ICF, disability and functioning are viewed as outcomes of interaction between health conditions and contextual factors. Participation is defined as involvement in a life situation. In this study disability is understood

as relational and refers to the interaction between the individual and structural factors, and pays attention to how the *experience* of a disabled person results from the relationship between factors intrinsic to the individual and extrinsic factors arising from the wider context in which he or she finds him/herself (Shakespeare 2006, 55). I use the word impairment when referring to physical (or cognitive) loss of function.

Before leaving the ICF some critiques can be mentioned: aspects of patient experience related to having an impairment, such as the burden of medical care and worries about health status, are not covered by the ICF. Other criticism of the model includes that too much attention is given to capacity and what the person *can do* in favour of what the person *is doing* in everyday life, and not treating aspects of impairment as the experience of burden and feelings of anxiety (Egilson and Traustadóttir 2009; Majnemer 2009; McConachie et al. 2006). Traditionally, rehabilitation interventions focus on minimizing impairment and maximizing function across domains of activity (Majnemer 2009, 3). More knowledge about the positive and negative factors affecting participation is called for (Majnemer 2009, Majnemer et al. 2008). It is therefore considered important to establish models or measurements that include the child's experience, a subject that is central in the discussions related to paediatric rehabilitation.

Few of the studies mentioned investigate the experiences of children with disabilities and their participation in outpatient paediatric rehabilitation consultations. There is a lack of research that provides in-depth descriptions and analyses to supplement contemporary findings that focus on how children express themselves when interacting with professionals, or that highlight the reasons and arguments children give themselves for being actively involved in decision-making in paediatric rehabilitation. Another focus is how children's bodies are materialized during consultations – for example as 'impaired' or disabled (Coleman-Fountain and McLaughlin 2013). In line with this, this thesis adds documentation from children and professionals describing their experiences from participating in consultations.

The research context: paediatric rehabilitation

The paediatric rehabilitation services are a complex system regulated by four different political ministries. In practice this system extends across municipal, county (primary), regional (secondary) and national levels. The research project of this dissertation concerns paediatric rehabilitation in the specialist healthcare services at regional level. The specialist healthcare services are organized in various ways in the different health trusts. The range of

services they offer includes diagnostics and functional assessment, rehabilitation training of physical functioning and skills training, intensive specialized training, patient training devices, and counselling the primary health care service (Directorate of Health 2009[1]). Professionals working in the services have varied professional backgrounds, and their work is highly interdisciplinary. For children with physical disabilities, healthcare professionals specialized in physiotherapy and paediatrics are the professional groups they cooperate with regularly, but also with professionals trained in psychology and pedagogy.

The professionals working in paediatric rehabilitation represent different professional knowledge of assessment and treatment. For example, occupational therapists claim human activity as their domain of concern. Medicine and nursing rely heavily on descriptive documentation on biological, physiological and psychological phenomena, based on scientific observable conditions (DePoy and Gilson 2011). Physiotherapy has a tradition from physiology/training and medical practice, but has activity and participation as a major part of its practice (Østensjø and Øien 2012).

Paediatric Rehabilitation is defined as:

> […] time and planned processes with clear goals and means, where several parties cooperate in providing necessary support to the patient or user's own efforts in order to achieve optimal functional and coping skills, independence and participation in everyday social life and in society (Regulations on habilitation and rehabilitation 2011[2]).

It is the duty of the specialist healthcare service to make the patient and user actively involved in the planning and decision-making process concerning their own rehabilitation (Regulations on habilitation and rehabilitation 2011, section 4). According to the Act on patients' and users' rights, children have the right to be heard in healthcare and medical decisions from the age of 12 (Sandberg 2009). However, in practice professionals need to consult the child – in addition to the parents – and to create active communication with the child to obtain information (King et al. 2012). Although professionals maintain that they are aware of the legislation governing children's participation, in practice they give it little thought.

[1]Helsedirektoratet 2009
[2]My translation of: Habilitering og rehabilitering er tidsavgrensede, planlagte prosesser med klare mål og virkemidler, hvor flere aktører samarbeider om å gi nødvendig bistand til pasientens og brukerens egen innsats for å oppnå best mulig funksjons- og mestringsevne, selvstendighet og deltakelse sosialt og i samfunnet (Forskrift om habilitering og rehabilitering 2011).

Children's participation in paediatric rehabilitation is often seen from the perspective of the parents, associated with the parent- and family-centred focus (Øien et al. 2010). As mentioned earlier in the introduction, children are often not included in conversations, and parents talk on behalf of their children (Feldman et al. 2012; Garth, Murphy and Reddihough 2009; van den Brink-Muinen et al. 2006). However, some recent studies highlight children's own experience of participating in paediatric rehabilitation (Garth, Murphy and Reddihough 2009). This dissertation seeks to highlight the theme 'children's participation' by observing encounters in consultations, by exploring children's own experiences, and by investigating professionals' experiences in comparison to the child's experiences. The study investigates individual cases in depth by using different theoretical perspectives in order to improve our understanding of children's participation in paediatric rehabilitation. In addition, the study addresses disability and what children and professionals use as a frame of reference for understanding the social and biological dimensions related to disability and impairment.

The term paediatric rehabilitation is used in the papers and will therefore be used throughout the thesis. Paediatric rehabilitation is conventionally used internationally rather than 'habilitation', which is the Scandinavian word for children's rehabilitation. When I refer to Norwegian regulations I write 'habilitation' in the references in accordance with official translations.

I understand professional work as an encounter between professionals, children and parents.

I understand identity as a process to become like others and simultaneously to be different from the others. It is the verb to identify that is explored rather than the noun identity: the verb makes identity a process that happens between people and opens for investigations (Whyte 2009).

Purpose

The purpose of the research project is to investigate children's participation in paediatric rehabilitation by:

- Exploring children's experiences from participating in consultations, and professionals' experiences from working with children in consultations.
- Exploring professionals' work with children during consultations.

The research project aims to contribute information that provides insight into what children's participation is about and what restricts or gives the child the opportunity to participate in

decision-making processes. It will also discuss the possible implications this may have for both professional practice in paediatric rehabilitation and further research on children's participation.

Chapter 2: Research themes

In this chapter I will elaborate on the themes that are discussed and analysed in the three papers of this thesis. I will use this chapter to discuss the relationship between participation, being a person and paediatric rehabilitation – the central themes of the thesis that will be brought up again in the discussion chapter. I will elaborate on these themes by explaining which debates and traditions the themes belong to. I find this important since the discussions on participation and paediatric rehabilitation provide insight into what they actually concern and how they can be understood. I will discuss the evolvement and definitions of (paediatric) rehabilitation and disability in order to situate paediatric rehabilitation in a brief historical perspective. This will emphasize the normative impact that underlies paediatric rehabilitation practice.

I will start by describing and highlighting some perspectives on children's participation, with emphasis on being and becoming a child/person. I will discuss some implications of seeing children as having the ability to act with agency by emphasizing the relationship between agency and context. Agency is not treated and discussed fully in the papers and I will therefore pay agency some attention. I find the debates on agency crucial and in accordance with the theoretical perspectives applied in the three papers.

Researching children's participation

Nigel Thomas and Barry Percy-Smith (2010) write in their introduction that: "... relying on adults to take account for children's views is insufficient to ensure children's participation rights." Participation lacks its own distinctive theoretical framework: its meaning is ambiguous, and there is uncertainty about what the term actually means. However, there is a growing awareness that it is most meaningful when it is rooted in children's everyday life (Thomas and Percy-Smith 2010, introduction). Participation describes what people do in different activities. It describes different forms of social engagement and it is constituted as a right, and by emphasizing the implementation of article 12 of the Convention of the Rights of the Child – the child's right to express a view – recognition and respect for children and their life is required (Lansdown 2010). Although participation as a right and participation as engagement in social life cannot be separated, the two dimensions of participation do highlight some different discussions.

Research on participation and how to give children voices draws attention to communication between the child and adults. Fitzgerald et al. (2010, 293-305) point out that participation is often seen as a 'struggle' *for* recognition, communicated through a monologue. They suggest paying attention to the dialogue as it emphasizes participation as a 'struggle' *over* recognition. Through dialogue, children's own views are respected and favour equality. The dialogue paves the way for communication where the child may become an active participant. Talking with children implies new insights and marks the importance of including experience in order to understand and improve practice in the arenas where the child participates. As Lansdown (2010) highlights, the lack of recognition of children's right to be heard is a lack of understanding that children have the capacity to contribute in decision-making. Too often adults underestimate children's capacities, or fail to appreciate the value of children's opinions.

The opportunity for children to participate and to be heard in situations where adults also take part relies on goodwill from adults. In medical practice, healthcare professionals need to provide information that is understandable to the child and need to spend time talking to the child. (King et al 2012; Lambert, Glacken and McCarron 2008). Healthcare professionals have a duty to contribute to children's opportunity to be actively involved in planning their own rehabilitation.

Children's participation has been studied from different perspectives and has brought insights into general and specific levels of children's everyday life (Clavering and McLaughlin 2010; Thomas and Percy-Smith 2010). During the twentieth century, children were given rights to influence the processes and institutions that affect their lives (Oswell 2013, 3–4). Children are given agency, in the sense that they are perceived to have the capacity to do things and to influence situations and the outcome of decisions. Children and youths are given the right to be heard through local councils and governmental and non-governmental organisations (Hinton et al. 2008). However it can still be questioned if children are recognized as democratic agents (O'Toole and Gale 2008). Children acquire citizenship through participating in different arenas, and studies on children and citizenship emphasize how social and welfare policies on childhood are being framed within the social, political, and legislative context in society (Austin 2010; James and James 2008; Kjørholt 2008). However, this does not imply that children themselves experience that they can affect situations and the decisions being made, or that they participate and are listened to.

The different perspectives and ways of viewing the child with competence that is important to listen to are described as a shift from seeing the children primarily through the adults to seeing the child as autonomous, and as a social actor with competence in his or her own right. The shift implies attention to the contexts of the child's everyday life, encounters and performance, and the process of identity making (Christensen and James 2008). The shift has turned attention to what *being* a child is and what children do in their everyday life, in contrast to focusing on children as *becoming* adults.

The distinction between the child as *being* and the child as *becoming* refers to two different understandings of how to relate to the child, justified by different morals. The distinction stems from the work of Durkheim, where the child is seen as developing from being weak to becoming strong and where collective institutions, such as family and school, shape children into becoming adults (Oswell 2013, 38–39). The sociological study of childhood thereby addresses how different institutions affect children and childhood. A similar understanding of becoming can be seen in psychology – for example in the work of Jean Piaget and his studies on how children develop emotionally and cognitively according to developmental stages. Even though the focus on the study of children and childhood is investigated differently in these two traditions, the similarity is the understanding of development as 'fixed' according to developmental stages. These views on children have been widely criticized by scholars who regard childhood as a social construct, emphasizing the role of cultural context and the child as a social actor with competence in his or her own right (James and Prout 1997; Jenks 1996; Rogoff 2003).

Research on children has changed, from seeing the child as an object of study with adults working as proxies for the child to research with children as first-hand informants, and more recently also as researchers themselves (Alanen 2010; Christensen and James 2008; Kellet et al. 2010; Thomas and Percy-Smith 2010). Repositioning the child as a subject, rather than viewing it as an object of research, has implications for childhood research. The positioning of the researcher and the relationship between the child and the researcher relate to the more general cultural notions of power relations between adults and children (Christensen and James 2008; Christensen and Prout 2005; Gulbrandsen 2008; Mayall 2000; Ulvik 2007). The relationship between the researcher and the child will be discussed in chapter 3: Method and analytical framework.

Researching children as being: attention to experience

The emphasis on the child as *being* implies setting aside the normative values or desires of how we want children to turn out and rather focusing on the present and how they *experience* their lives. The sociological understanding of childhood as a social construction sees the child as an interactive player being shaped by persons and institutions, and where the child shapes them (families, schools etc.). Paying attention to being a child highlights the *experience of* being a child, and what the child *does* in everyday activities, and the way in which the two facets of children's everyday life are emphasized in childhood research varies (Christensen and James 2008, 3). Both the facets pay attention to the present and can be seen as a critique to childhood understood in the traditional sense described earlier. Sociological discussions concerning children and childhood have affected other disciplines that involve working with children. For example in the field of physical therapy the discussions about professional work in paediatric rehabilitation encourage professionals to investigate not only children's *capacity to do* activities (standardized, controlled-environment activities) but also to explore what children *are doing* and *how* they are experiencing their daily life activities (Majnemer 2009, McConachie et al. 2006; Law 2002).

Even though the shift has contributed with much insight, Gallacher and Gallegher (2008) underline that a problem with the 'new paradigm' can be that "…the static and coherent model of subjectivity as being makes it difficult to see through children's insistent and strikingly apparent changeability" (Gallacher and Gallegher 2008, 510). By this, they ask for attention to be paid to the events and the on-going process of being a person in different contexts over time.

Researching children's experiences can be seen as a way of approving children having the possibility to make a difference and of paying attention to children's perspectives. This is made relevant in papers 2 and 3 by describing the frameworks that children and professionals hold. To study experience is to pay attention to the children's perspectives and to approve the different perspectives children provide (Warming 2011). Seeing children's perspectives is a way to emphasize that children have diverse identities (Davis et al. 2008). This also applies for children with disabilities. However, what children say, their views, is (as it is with adults) dependent on the event, the interaction between those present in a particular situation and how the child positions her/himself in the situation. It is thus crucial to take into account the perspectives adults take with them into a situation concerning how children can contribute when discussing the child's opportunity to be listened to. For instance: do adults take with

them perspectives that promote or hinder children giving their views? To what extent do the professionals give insights from children precedence or not in decision-making processes? Papers 2 and 3 discuss and give insight into the different understandings and perspectives the children and the professionals use in their understanding of participation.

Voice and agency

Conducting research with children implies a view of children as sentient beings that can act with intention and as agents in their own life. This involves seeing the child with an entitlement to being considered a person with value and rights. Studying children's experiences concerns the child's consciousness and capability to work with agency (Greene and Hill 2005, chapter 1). Agency can be understood as the capacity to do things, and to make a difference. However, agency is not an innate capacity; it is produced in relationships and interaction with others (Oswell 2013; Davis et al. 2008). In such a view, agency (the individual actor) does not stand in opposition to the collective and structural conditions: agency and structural conditions are in a mutual relationship (Oswell 2013). Structural conditions may constrain the child's possibility to be seen with the ability, for example, to influence the decisions being made. Structural conditions, such as guidelines and institutional practices and professionals' practice, can prevent, oversee or ignore the child's agency. Papers 2 and 3, emphasize how children want to affect decisions, and how they react toward practices where they are prevented from participating in decision-making. Inviting children to tell about experiences from participating in consultations is to accept their experiences and their agency. Through their experiences, it may be possible to obtain information on how they experience their possibilities to contribute in decision-making.

Agency can also be explored by investigating what happens in encounters. Paper 1 addresses roles and what the participants do in consultations. One of the theoretical perspectives applied, (the theory from Bruno Latour and the Actor Network Theory), which will be discussed in the next chapter in the analysis of the consultation, addresses the interaction and connections between the actors (persons and objects) and how these affect the outcome of the consultation. In this perspective, agency is not seen as intentional: the agency lies in what happens in the situation and how notice is taken of it.

Children's agency can be emphasized in different ways. However, seeing children with the ability to make a difference is about listening to the child's view and experiences – giving children a voice. It is important to be aware of the limits of what focus on experience can tell us about other people. Individuals can report on their motivations and emotions only to the

extent that they are aware of them and only in the manner they have come to interpret them (Green and Hill 2005, 6). In this study children's experiences are investigated *per se*, as they are told by the children. By paying attention to children's experiences of participating in consultations, it is also the children's perspectives that are given a main role in contributing information about paediatric rehabilitation.

Children's participation stated as a right is a very explicit example of how children's identity is negotiated and regulated by law. Society has made a system for children with disabilities involving (re)habilitation to support participation in everyday activities.

Paediatric rehabilitation: being and becoming an active participant

Taking part in a paediatric rehabilitation programme is seen as a supportive intervention: the child participates in everyday life activities as other children do. At the same time, being enrolled on a paediatric rehabilitation programme constitutes disability in several ways, which can be discussed. The inclusion criteria for enrolment to a rehabilitation programme imply being defined as having a disability or being diagnosed with impairment. How the impairment or the disability is handled will vary according to whether children meet a specialist concerned about the physical impairment or whether they meet professionals concerned about the child's everyday life. Taking part in a rehabilitation programme is time-consuming, and it often breaks up schooldays, leisure time and even weeks if there is need for rehabilitation stays. Having a disability may also be space-consuming if technical aids are necessary, and extra space for storage is frequently required. This concerns planning how to live a life that makes it possible to participate in everyday activities. If the planning is absent, it can exclude the child from participating in activities. Rehabilitation, all the different arenas the child participates in within the rehabilitation chain, form a 'platform' for identification. Attention to the experience of participating in these different arenas is crucial. In this study, the consultation is the arena investigated.

Attending consultations is one arena of many in the child's rehabilitation chain that provide the child with experiences affecting his or her self-perception. Children with disabilities experience doctors and physiotherapists examining their body function and capacity, classifying them as more or less 'atypical'. The doctors set diagnoses according to standards. Having an 'atypical' body function is a medical classification in accordance with existing medical and scientifically-based definitions of what is more or less typical or 'atypical'. Diagnoses and the child's condition are filed and reported to the hospital archives.

Historically, normal and abnormal have been used in medical practice, where abnormality was in focus and perceived as a tragedy (Depoy and Gilson 2011). Even though, as Ingun Moser (2006, 139) writes: "…Medical discourses, methods and technology contribute in defining and implementing norms for what is normal nature as well as deviant nature." The connotation related to the dichotomy normal-abnormal is negatively valued, as is atypical. Typical is a way to escape the value-laden descriptions of difference (Depoy and Gilson 2011). Although impairment opens for medical classifications according to degrees of being atypical, the experience of being (dis)abled may not be felt as atypical by the person in question, and it is also important to be reminded of this when classifying persons with disabilities. In other words, children are classified according to a set of medical procedures, organized according to hospital routines. To quote Ingstad and Whyte:

> "… disability in Europe and North America exists within – and is created by – a framework of state, legal, economic, and biomedical institutions. Concepts of personhood, identity, and value, while not reducible to institutions, are nevertheless shaped by them. Citizenship, compensation, and value lost through impairment and added through rehabilitation are institutionally reinforced constituents of disability as a cultural construct. So is also the idea that disability is a medical condition for which technical (…) expertise is the answer." (1995, 10)

Underlying rehabilitation plans and strategies are ideas of how to assist people with congenital or acquired disabilities to live a worthy life and to participate in daily activities. In many western countries with welfare systems, belief in equality (same rights, same opportunities) is embedded in the development and evolvement of rehabilitation (Ingstad and Whyte 1995). This became particularly visible after the First World War. A brief account of the evolvement of the rehabilitation system, of which paediatric rehabilitation is part, can be mentioned as it highlights the relationship between paediatric rehabilitation/rehabilitation and how disability is defined.

Evolvement of paediatric rehabilitation through rehabilitation

A profound new way of thinking about rehabilitation came to the fore after the First World War. Attention was on the war veterans, and subsequently on 'the disabled', with the goal of making them fit into modern production society (DePoy and Gilson 2011; Grue 2004; Ingstad and Whyte 1995; Solvang and Slettebø 2012; Stiker 1999). Marte Feiring (2012) argues that the rehabilitation system in Norway can be traced back to the Norwegian schools for the 'abnormal' (special schools), medical practice in the interwar period, professional practice,

and the development of the registration and documentation of knowledge. In the mid-1960s doctors were given the authority to evaluate people's need for rehabilitation and special welfare support. During the same period a definition of disability became official, which included people being restricted from participation in education, work and leisure time activities (Feiring 2012). And with the new definition of disability came new ways of categorizing different forms of disability.

As mentioned there was a change politically in how disability was understood as early as the 1960s – the need for 'normalizing' people with disabilities lives through not making segregated initiatives and solutions but initiatives enforcing the integration of disabled people into the ordinary system for the citizens (Grue 2004, 190). Attention to the living conditions of people with disabilities and society's responsibility and rights as well as disability caused by social, material and economic barriers must also be seen in relation to changes internationally. The International Year of Disabled Persons in 1981 and the UN Decade for Disabled Persons (1983–1992) provided a framework for national work on programmes and strategic planning for people with disabilities. From the 1980s, focus on goals and implementation attracted greater attention through action plans (Grue 2004, 191–204).

Teams of professionals were established towards the end of the 1980s, connected to the regional paediatric hospital wards. The purpose was to evaluate disabled children's needs for assistance and to provide professionals working in the community health services with advice and guidance in their work with the children and the children's families (Normann, Sandvin and Thommesen 2003, 33)

For children, the political focus on 'normalization' and integration became visible through the downsizing of special schools and institutions for children with disabilities (and adults with developmental difficulties) (Normann, Sandvin and Thommesen 2003; Tøssebro and Lundeby 2002). Perceptions of integration build on the norm of equality: that children with disabilities must be given access to participation in the same arenas as their peers if they are to be accepted as children without disabilities. The paediatric rehabilitation services evaluate whether the child needs assistive devices and possible solutions for accessibility (for example ramps), and they submit relevant proposals. In addition, they also often contribute information that teachers can use when planning adapted education if this is required for the child. These are measures that help the child to participate successfully in school and everyday life activities. In addition, to achieve a successful integration – today more commonly described

as successful participation – the services that provide assistance to fulfil the child's needs must cooperate in a satisfactory way, and these services must incorporate the perspective of the individual's overall needs in their professional work.

An important goal in the paediatric rehabilitation policy for children with disabilities is to achieve active participation in school and leisure activities. The planning for participation in school and in social activities may start in the specialist healthcare services. Like the other services, the specialist service is supposed to contribute solutions in accordance with the child's overall needs, and it is therefore appropriate to direct attention to how social aspects and the child's overall needs are implemented in paediatric rehabilitation practice.

The definition and evolvement of rehabilitation and paediatric rehabilitation was and still is a political and normative project. Although the rehabilitation system may seem like a system that represents tolerance, Stiker (1999) – a French historian working on the history of disability and rehabilitation – argues that it is grounded on the philosophy of not tolerating difference and deviancy. Rehabilitation is society's way of framing disability and a way of dealing with the impairment guided by criteria and regulations. Those with disabilities are given rights, but at the same time they are named with a specificity that constitutes an identity marker (Stiker 1999, 133). Stiker underlines that difference must be conceived as 'normal', and therefore that society must recognize differences among people.

There is an active interplay between how rehabilitation is carried out in practice and how impairment and disability are understood. Norms and practices for how to take care of disabled children and adults were practised long before the concept of disability was established. Historically impairment is recognized as bodily difference, and cultures have categorized and still categorize such difference in various ways. Even though attention to impairment and the medical understanding of disability have changed over time, many of the studies on disability are closely connected to medicine by their focus on biomedical factors. In the following I will direct attention to the study of difference in disability studies.

Disability

DePoy and Gilson (2009) emphasize how disability studies during the last few decades consist of many theories and responses. However, most common is a divide between biological and essential explanations or theories highlighting the construction of disability and impairment. Using biomedical diagnostics as explanations for disability emphasizes body function and body structure, and is comparatively observed through a series of methods and

examinations. The most frequently and empirically observed is prescribing standards and norms. Theories emphasizing the disabling forces to explain disability see individuals and their activities as diverse rather than fitting into defined categories, and go under the rubric of constructed explanations for disability. The emergence of studies of disability referred to as 'critical disability studies' has influenced the study of disability (Goodley 2013). These are studies that use different theoretical perspectives to describe the materiality of the body and how disabled identity or subjectivities are constituted through local and global processes. They also analyse how other domains such as gender and class intersect what disability is about (Garland-Thomson 2011; Shakespeare 2004 and 2005). These are studies that emphasize how social discourse around disability defines or explains what disability concerns.

The social model of disability highlights the barriers that prevent people from taking part in society. The model is concerned with disability rather than impairment. Disabled people who face material barriers such as stairs, buildings etc. are given primacy of attention, which excludes other forms of disability. Other critiques are the lack of problematizing gender, class, ethnicity, age, and personal experiences (Shakespeare 2006; Thomas 1999). By ignoring impairment and the experience of living with impairment, the model makes a sharp distinction between public and private, and between the personal and social self. However, the social model has given disability a new content that emphasizes how categories are constructed socially and gives disabled people rights. This is one main reason for the revision of earlier versions of the ICF and the International Classification of Impairments, Disabilities and Handicaps (ICIHD). Contemporary disability studies favour a relational model of disability, many of them arguing for the social model although accepting impairment as a biological essence and addressing experiences such as physical pain which may be caused by the impairment (Garland-Thomson 2011; Morris 2001; Wendell 2001). In addition, these scholars bring into their analyses how disability is constructed socially and discursively and through interaction, and they have pointed out the oppressive dimensions that are connected to disability (Morris 2001; Thomas 1999).

Crucial in the studies on bodily difference are the discussions about categorizations of difference and how people position themselves and are positioned by others according to categories (Coleman-Fountain and McLaughlin 2013; Morris 1992; Morris 2001; Wendell 1996). Unlike anthropological or cross-cultural studies that document how difference is understood and impacts social organization and personhood (Ingstad and Whyte 1995), the

study of difference in disability studies also discusses the consequences of emphasizing categories. In disability rights' activism, impairment works as a unifying category where the difference (the impairment or the disability) is used to achieve rights and acceptance for being different (Thomas1995 and 2004; Morris 2001). Identity as disabled is highlighted and serves as a way to achieve recognition as disabled with the right to be heard. However, as Susan Wendell (1996) points out, it is important that the disability or the impairment does not overshadow individuality, gender, class, ethnicity, and age. Wendell (1996) reminds us of the diverse identities of children and adults. She writes:

> "It is therefore important not to assume that people with disabilities identify with all others who have disabilities or share a single perspective on disability (or anything else), or that having a disability is the most important aspect of a person's identity or social position." (Wendell 1996, 70)

This study investigates the aspects of children that are emphasized during consultations. Wendell also writes about how categories address differences, and states that some categories imply fewer differences than others. The point is to identify the information provided by the categories that are invented to describe whether people are different or not (Wendell 1996. 69-73).

The relational understanding of disability is concerned with disability as social and constructed, but the biological essence is not rejected.

In the deconstructionist view, where meaning is solely seen as given through discourses, both disability as social and impairment as biological are seen as constructed, and identity cannot be read from categories such as 'disabled' or 'impaired' (Thomas 1999, 114-115). Sameness and difference are not fixed, but are fluid and continually in the process of construction and maintenance through discursive practices and performativity. Identity politics is seen as highly problematic from this perspective, as the self is in constant change and is being constructed and reconstructed through interaction and by engaging in conversations.

In the context of paediatric rehabilitation, the body with impairment is given special attention. It is therefore appropriate to investigate how the body (the child) is materialized – for example as a body with impairment being atypical or with attention to the disability and the social experience of living with a disability. To quote Jenny Morris 2001: "… it is important to assert that anatomy is not destiny and that it is instead the disabling barriers "out there" which

determine our quality of life" (Morris 2001, 9). I would like to draw attention to how in paediatric rehabilitation the professionals talk to the children during consultations about the fact that anatomy is not destiny, and how they pay attention to the children's own experiences of living "out there". How materialization of the body affects children's participation during consultations is explored in paper 2.

Attention to social barriers and disabled people's own experiences has revealed crucial insights into how society can make people become disabled and the discrimination of disabled people, and also how categorization always changes according to time and place in history. The constructionist perspective is an important critique to medical practice, and a reminder of how medical practices have changed through history.

Disability in anthropology

This is a study grounded in the field of social anthropology and therefore I find it relevant to give more details about the study of disability in anthropology. Attention to impairment and disability in the field of anthropology has increased in accordance with greater research interest in disability during the last few decades (Shuttleworth and Kasnitz 2004). It was not until the mid- to late-1970s and early 1980s that research was published on people with various impairment-disability experiences. These authors were medical anthropologists who created space in the subdiscipline of the study of cognitive, behavioural and physical difference and impairment-disability. Impairment-disability still receives less attention than illness and healing. One criticism of the study of impairment-disability in medical anthropology is that it focuses too much on cause and cure, and on treating disability as a disease by highlighting the restorative thought related to disability. For people born with an impairment, the dynamics of hope take paths that are different from those for cure (Shuttleworth and Kasnitz 2004). Disability and the evaluation of others in contrast to the reflexive sense of self (Ingstad and Whyte 1995, 11) is one of the basic questions in cross-cultural research on disability. It asks how biological impairment relates to personhood and to culturally defined differences among individuals. Moreover, these studies investigate the kind of support and assistance that is offered to people with impairment in different cultures, and this research project can be seen as influenced by this perspective.

Applying social theory to understand participation in paediatric rehabilitation gives insights into what affects and defines paediatric rehabilitation at a certain time in history. As I see it, it is a way to view medical practice in a critical light – not to deny the biological components of

impairment but to highlight how this works in social interaction. The rehabilitation practice represents a system that organizes, classifies and treats children with disabilities. I see the reinforcement as being made in the interaction between people (Goffman1975, 1967), but also that the practice is reinforced by ideas of classification (Hacking 2004).

So far a review has been given of the themes that are researched in this study. I have given these themes attention as a supplement to the papers and as a background for directing the placement of the research study methodologically and theoretically.

Chapter 3: Method and analytical framework

In this chapter I will discuss how the methods and theories applied can be placed scientifically. The choice of design and the methods applied in the project will be considered. The sample, information gathering, my role as a researcher, transferability and dissemination of the findings will be described. I will also explain the process of analysis. Different theoretical perspectives are used to interpret the research findings. I will try to convey my experiences as a researcher and to illustrate my conclusions in such a way that the reader will gain insight into the knowledge that is acquired and that I have played a part in producing.

The research questions give direction to what will be studied and how it will be studied. They also provide information about the tradition that the research project can be said to belong to (Kvale and Brinkmann 2009; Silverman 2004a). This research project explores lived experiences by using ethnographic methods that include observation, interviews and conversations. The material is analysed by social theories representing different perspectives on how to study social life.

Overall the study explores and interprets experiences and social interaction in relation to their context. Furthermore, what the experiences and social interaction that takes place during consultations can mean is explored. These experiences and social interaction provide information about paediatric rehabilitation practice (context). An underlying understanding of the project is that knowledge is constructed through interaction between people. This applies to the research process as well: knowledge is produced in a research process that the researcher is part of. This study is critical to the use of rigid methods that reject subjectivity and favour 'objectivity' when doing qualitative research. Reflexivity is central in qualitative research, and can be read as a critique of positivistic research traditions. In addition, the project raises critical questions about the empirical findings (the rehabilitation practice). The study aims to offer a dynamic – and hopefully not a rigid – account of qualitative research.

Contemporary qualitative research in social anthropology – and in other disciplines such as sociology, psychology, education, and health care and nursing – highlights the importance of understanding the qualitative method as a process where the researcher is the 'tool' for performing the research. The researcher's subjectivity and preconceptions are part of the analytical process and are not seen a source of bias (Fine 2007; Gubrium and Holstein 2009; Haavind 2000; Kvale and Brinkmann 2009; Silverman 2004b; Søndergaard 2000).

Researching people's lived experiences brings the role of the researcher to the fore during the research process (Alvesson and Sköldberg 2000, 4–9). Reflexivity is to think through the different factors affecting our descriptions of social life (Miller and Fox 2004), including displaying the closeness to the persons we do research with:

> "Our descriptions cannot be separated from the objects, persons or circumstances that they describe or the language that we use to describe them." (Miller and Fox 2004, 36)

Being reflexive and critical of how research is conducted is essential in much ethnographic writing, and it has been addressed in different ways (Foley 2002; Marcus and Fischer 1986). A more critical use of reflexivity on the researchers themselves became prominent from the mid-1980s (ibid). Reflexivity is about the positioning of the researcher in the research process and in ethnographic writing, and it is about being reflexive about the use of theory. Reflexivity entails being self-critical as a researcher and being aware of the limitations one has as an interpreter. In the field of ethnography today there are different forms of writing oneself into the research project by making one's own experience a central part of the analyses (auto-ethnographies), or being more distant and using reflexivity in a more theoretical way (Foley 2010). Theoretical reflexivity concerns how the theories applied are grounded in the everyday life practices of the subjects, which can be emphasized differently. Theoretical reflexivity is about how the researcher reflects upon the knowledge being produced during the research process and the choices being made, and how the researcher is part of knowledge production. Knowledge production in narratives is explored and emphasized through the individual story, the storyteller and the persons involved, while networks of relations are explored in the Actor Network Theory: how relationships are connected. The perspectives address social life in different ways, and thereby also reflexivity.

A research study elicits different forms of reflexivity and is related to both the methods and the theories applied. For this project, reflexivity is discussed in relation to theory and to how the research is conducted, where my subjectivity is a crucial part of the process.

The research process has been a continuous process of asking questions, redirecting theoretical questions and finding 'better' ways to work when gathering information and analysing data.

Combining observation and interviews

Observation and interviews are used as information-gathering methods to acquire information about professional work and children's participation. Applying these two methods addresses the questions about and reasons for combining observation and interviewing, which I would like to emphasize. Atkinson and Coffey (2003) point out how the use of participant observation and interviewing rests on the distinction between what is done and what is said. In their article they discuss how participant observation has traditionally been seen as a more valid and trustworthy source of information gathering than the interview. However, they underline how observational studies from the 1950s and 1960s do not describe the actual action but what the informant says they do. Interviews have been criticized for not being as worthy as participant observation because they provide second-hand information about events. One problem, as Atkinson and Coffey (2003) assert, is how the combination of the two methods in itself does not make the study reliable and valid. The content of the data, the arguments and the descriptions of analytical choices, the coherence between data and analyses, as well as reflexivity on what kind of knowledge the method applied produces, all combine to make qualitative research reliable and valid.

The reasons for choosing observation in this project are to see what goes on during consultations and to find out how professionals work with children. Observing is a way of capturing tacit knowledge – the action not described by words. As mentioned in chapter 1, there are few studies that describe in detail what happens during consultations, and therefore I have chosen to present a description of a consultation in paper 1. Although observation is not chosen to validate what the professionals and the children say about consultations, it is seen as complementary. Conducting observation and interviews in themselves constitutes knowledge production. Observation provides situated knowledge, generating a distinct kind of account. Interviews also provide situated knowledge and are events in themselves (Holstein and Gubrium 2004, 14) – social events that give rise to particular versions of social analysis (Atkinson and Coffey 2003, 422). Challenges that arise using observation and interviews will be addressed later in the chapter.

Sample and recruitment procedures

The observation and group interviews with professionals were carried out at a paediatric rehabilitation centre. The sampling is on the basis of the research design and the research questions of the project. The participants were recruited through the paediatric rehabilitation

centre. Professionals working at a paediatric rehabilitation unit and children with experience of attending consultations are the main informants.

All paediatric rehabilitation centres in the south-eastern part of Norway that would not be too far to travel to on daily basis were considered appropriate for conducting research. Observation and interviews with the professionals were carried out periodically during the daytime over a time span of two and a half years. One centre gave a positive response quickly, and a meeting was arranged with one of the leaders. After some days the section leader at the rehabilitation centre decided that the centre should take part in the research project, and I was invited to present the project at a staff meeting. The employees at the centre were informed about the project, observation and interviews in advance. In addition, the employees were asked to consider if they wanted to participate in group interviews as well as being observed during consultations. Four professionals announced their interest shortly after they were asked, and two others volunteered later. At the meeting I informed those attending about the project and the methods that would be applied. The six professionals at the centre who volunteered to take part in group interviews were three physiotherapists, a doctor, a psychologist and one nurse. Three group interviews were carried out with them.

The children were recruited from the paediatric rehabilitation centre. The inclusion criteria for the children are:

- Children with a physical disability
- Relatively long experience from attending consultations, although not only youngsters: the age set for participating in the project was also those between the age of ten (or turning ten in the current year) and 15
- Minor or no cognitive disability

One person at the rehabilitation centre selected children who suited the inclusion criteria from the archives, and sent these families an invitation and information letter. A total of 43 families received the invitation. Families who wanted to participate signed the consent letter and returned it to me in the stamped and addressed envelope provided. Consent will be discussed under ethical considerations.

Nine children volunteered to participate as interviewees. Twenty children were set as a preliminary number of participants, although it was regarded as realistic to recruit 10-12 children.

In addition, 43 consultations with professionals and parent(s) with children were observed at the paediatric rehabilitation centre.

One of the six professional participants was a crucial contact person during the research period. This person is especially interested in the subject, wanted the project to be carried out at the paediatric rehabilitation unit, and worked as a door opener for the research project to be conducted. Although gatekeepers can be considered as crucial because they open doors, it is vital to be aware of the influence the person has at the institution since this may affect what people choose to relate. The gatekeeper influences the process of gaining confidence among the employees (Fangen 2010, 67–69). The other professionals' engagement in relating their experiences and opinions about the topics being discussed in conversations and interviews was high, so I therefore considered the gatekeeper's effect on the others to be not too dominating. Agreements and disagreements were easily discussed. I benefited from having a person who always had time to talk to me, and I found the person's reflections, due to interest in the research topic, inspiring. They also seemed to inspire the others in the group.

Conducting observation

Professionals at the paediatric rehabilitation unit were observed during consultations, with children and parents present. I use the word observation rather than participation because although I was present during consultations I did not participate in any tasks performed or in the conversations that went on during the consultation. I took part in the event by sitting on a chair or bench observing the interaction between the professionals, the child and parent(s). Before the consultations I had made an appointment with one of the six professionals to join them in consultations. I was informed about the consultation and the children and parents who were coming for examination. The parents and the children attending the consultation scheduled for the appointment were informed by a consent letter sent to them by post before the consultation. If the family accepted having a researcher observing the consultation, they were asked to bring the signed consent letter with them to the consultation. During the consultations I did not usually sit together with the child, the parents and the professionals around the table. In many cases, the professional(s) and I sat down afterwards to discuss the consultation.

Positioning myself

As a non-professional I did not perform any tasks and did not join conversations, ask questions or initiate conversations. Nonetheless the professionals and other participants took notice of my presence in different ways, and I was also affected by what went on. I was

familiar with conducting observation and interviews with children with disabilities and teachers in school from earlier work, but conducting observation at a paediatric rehabilitation centre was a new setting for me. I considered myself an 'outsider'. I had no experience of working at hospitals with children with disabilities, and no experience of medical and healthcare professionals working with children with disabilities. This lack of familiarity with the setting reduced the possibility of taking things for granted, but also meant that I could 'miss' important things going on during consultations. In addition, as a researcher my preconceptions affect what I observed, the questions I asked the professionals before and after consultations, and also the analyses, which I will address later in the chapter. During the observation I could only 'consult' my preconceptions by being aware of not looking for things I thought would happen during consultations – for example that the physiotherapist is more attentive to the child than the doctor, and that the doctor talks more to the parents than the physiotherapist. In addition, I made the preconceptions into questions by explaining them during the conversations with the professionals, or by bringing them forward as questions or topics for the group interview. For example, I could ask "How do you allocate tasks between you during consultations?" And thereby investigate their descriptions by asking "Is this usual, what may be different, or has it always been like this?"

Positioning myself as an outsider demanded some way of displaying for the participants that I was a novice. Therefore I asked questions, and told them about my preconceptions. As a researcher, I am an outsider entering their work territory, doing research 'on' them. The power that can be exercised as an observer, and the vulnerability or unpleasant feeling that being observed may produce, should be handled with care. Jokes could arise – such as comments from the staff at the centre like 'you're the expert', 'it depends on what you want me to answer', and sceptical comments like 'how is it possible to generalize from the observations'. Personally I interpreted these comments from the professionals as a way of contesting my role as researcher, displaying their own positions as educated professionals, in addition to them being somewhat insecure about what I would do with the observation. I took these questions seriously by explaining the reason for conducting the project and for doing qualitative research. In addition, I put emphasis on the dissemination of the findings, which I will come back to below.

Being present during consultations affected the professionals and the other participants, and my presence was discussed during one of the group interviews. Some comments can be mentioned:

> "It's amazing, but I thought that having you observing me during a consultation would be problematic, but it didn't feel so. It was just as if you weren't there. You just sat there very quietly and I forgot you."

> "At the beginning one gets a bit more aware. So, maybe then (during the first observations) you didn't get the 'right impression'. I believe one thinks about it at the start, then forgets it."

> "You never know how a consultation will turn out, how you will cooperate with the child, and it's difficult to plan before the consultation. There are different ways of communicating with the child and the parents […]. It varies how the child reacts to conversations between the adults. And with you present – I thought: wow, then I must try my best and do all the things I planned to do. So it was a bit stressful because it was unusual. It's different (a different experience) having a new patient than having one you know. One isn't as relaxed, and when you're there, you're an extra factor. But after some rounds with you present I forgot it. I do also think that it's stimulating to have you there because I find this topic interesting. […]. It's important that the child feels comfortable during and after a consultation. And I find the conversations we have with you after the consultations very positive."

Instead of turning the observer effect on the professionals into a problem, it was turned into a crucial part of the research process (Atkinson and Coffey 2004; Miller and Fox 2004).The informants' awareness of my presence and their thoughts about being observed during consultations are crucial as they give information about what kind of knowledge that is produced from being observed. The professionals wanted to talk with me after the consultations, and we sat down after the consultations for aconveration. Observation may be a possible stressful situation for those being observed. The informal conversations gave me a chance to ask questions about consultations. The professionals usually had some reflections they wanted to share with me, or they were curious about my reflections. This provided important information that was valuable for both analysing the observations and as topics relevant to discuss during the group interviews. The participants' reflections after the interviews opened for deeper insights, as well as giving me the chance to discuss 'findings' (Middelthon 2001, 22–27). One of the participants said:

> "I've become much more aware of the importance of talking about what went on during the consultation afterwards. It may improve what we're doing. […]. I think it's been very interesting to have you observing. I don't find it stressful, but it makes me more aware of what I do. Then I forget that you're observing. […]. We're used to having many persons present during consultations, but the opportunity to have someone seeing the situation from 'the outside" is very unique and important. […]. I want to improve my work, and you ask questions and make reflections that contribute to this."

The parents and the child were also affected by my presence. Often parents looked at me when the conversation was taking place, and sometimes they even asked "Why don't you sit with us?" Only performing observation and not conducting participant observation reduces the opportunity to change between roles or positions as a strategy to acquire knowledge (Fangen 2010:85–86; Wadel 1992, 45–58). However, I found it important to use my awareness of the other participants' reactions to my presence. Where I placed myself physically during the consultation affected my own experience of being present. I noticed that the parents did not look at me very often when I sat at a distance from them. The children, on the other hand, took more notice of me by looking at me and smiling at me when I sat at a distance from the parents and the professionals. I felt more comfortable sitting at distance from the participants during the consultations. For example, I found it hard to take notes if we were in a small room sitting close to the other participants.

Note taking

During the first observations that were conducted I did not take notes because I wanted the professionals to get used to my presence. However, after only some observation sessions the professionals wanted me to take notes so I could write down all the details. In the rounds of observation, I found it very intense to observe and write at the same time. Therefore, immediately after the consultation or after the conversation with the professionals, I wrote down my observations as I remembered them. After a while I started to take notes during the consultations. Parents, children or the professionals did not seem take more notice of me by looking at me when I took notes. When parents brought up topics that I considered to be sensitive and private, I stopped taking notes so as not to prevent them from having an open dialogue with the professionals. It may be the case that the parents would not have minded if I had taken notes, but I decided to use my own sense of what was right or wrong in the situation.

Sometimes it was hard to write down the whole conversation verbatim, and I therefore used keywords and completed the sentences after the consultation. In addition, I wrote down my own thoughts and feelings and topics that came to my mind to be addressed in the following consultations. I also thought about possible theoretical perspectives or concepts that could be applicable for analysing the empirical material. Reflections related to data and theoretical insights were an inseparable process. I consider the observations, the notes I took and how I followed up questions as data, since this forms part of the productions of knowledge (Latour 2005, 133–136).

Interviews

Taking part in an interview can be seen as a social interaction, and the stories that are told during an interview are products of the talk between the interviewer and the interviewees (Holstein and Gubrium 2004, 143).Meaning and understanding of happenings and topics are produced during the interview, which forms the basis for further analyses of the data (Haavind 2000, 19–20).

The qualitative interview is one way to study lived experience from a person's point of view. Experience can be personal, referring to emotions and thoughts, or it can be a description of what happens in different situations. However, emotions and thoughts are usually connected to happenings in situations. In life mode interviews the child's (person's) experiences and descriptions of a specific situation are emphasized and thereby invite the person to reflect on what the happening is about. The interviews with children are inspired by the life mode interview and will be explained below (Haavind 1987).

Conducting interviews with the children

Two rounds of interviews were conducted. The interviews were carried out at the children's homes. Two of the interviews were conducted at the children's school on agreement with the school. This was suggested by the parent out of convenience for the child and me. One interview was carried out at my workplace since the child being interviewed lived far away, so the mother offered to meet for the interview on the same day as their doctor's appointment near the university college. Before all the interviews with the children, I phoned the parents and we arranged a day for the interview. When I came to their homes, I was welcomed by the family, and we all talked about whether I had had difficulty in finding the right way to their house. Some of the parents could say that their son or daughter had been looking forward to the interview with me. If I met the interviewee at school, we talked about the school and if he/she liked going there. They had planned where we should sit during the interview: in the

kitchen, living room or the child's room. When we sat down, the child and I, we talked about the research project. I repeated the purpose, and asked if they still wanted to participate. They were invited to ask questions. Few of them had questions to ask, but they found it relevant to contribute experiences. I asked if it was acceptable if I had the audio recorder on. The child was then invited to tell me about the last consultation at the paediatric rehabilitation centre.

The first interviews lasted between 45 minutes and two hours. During the interviews I did not take many notes. After the interview I wrote down reflections.

A follow-up interview was carried out for seven of the children. The second interview was used to clarify things they had told me in the first interview. In the second round of interviews with the children, the conversations were concentrated on the themes that had emerged during the first interview which needed clarification or further investigation. When comparing the interviews, themes that emerged as important could be brought up as topics for discussion. The second round of interviews lasted between 30–50 minutes. Before we had started the second interview, or after the interview, we spent some time talking about the experiences that were revealed through the interviews, and about reflections I had on the observations being conducted at the paediatric rehabilitation centre. During the second interview, the topic of children's participation in decision-making was investigated further.

One reason for not interviewing the parent(s) but only the children is that the primary interest is to get information from the children themselves. I also wanted the children to see that they were my primary source of information and not their parents. Children may have difficulty in believing that adults will take their view seriously if their experiences are dictated otherwise by adults (Greene and Hill 2005, 11). If the parent(s) was/were present during interviews, they often interrupted, and it made the child insecure in answering. In the second round of interviews the parents did not interrupt or were not present. I also experienced how the children could display resistance or disagreement when the parents had another opinion (described in paper 2).

Applying life mode interview

The life mode interview is a recognized method of investigating children's everyday life, their activities, relationships and experiences (Ulvik 2007, Gulbrandsen 1998 and 2008). It is not an interview that follows a strict pre-constructed interview guide but is rather organized along an axis of time. By introducing time as a principle for organizing the conversation, the interviewer can follow the child into concrete and detailed stories about what happened

yesterday, in the break at school or at the last consultation at the paediatric rehabilitation centre. The interview emphasizes what happens in specific situations, who participates and where the episodes take place. Further questions explore how the specific happening relates to what generally happens in the same place or same kind of situation. The child's stories are followed up by questions about whether this is what usually happens, and if not what does usually happen. The interviewee is also invited to share reflections. The participants together give content and meaning to what is discussed (Haavind 2000, 20). In addition, the interviewer asks if this practice is experienced as acceptable or if it should be different. The interview may open for further reflections on a theme. This process of exploration can be exemplified:

> During the first interview with one of the children it was explained that the last consultation was a special one because they only measured walking capacity, and the professionals did not ask any questions concerning school or leisure time. I therefore asked:
>
> Interviewer: Do 'Ann' and 'Solveig' (the professionals the child usually meets at consultations) ask you questions about school and leisure time?
>
> Child: Yes, they do.
>
> *I: What do think of that?*
>
> C: It's fine.
>
> I: If you compare talking about body function and talking about how things are on daily basis, what is your immediate thought?
>
> C: I think talking about how my feet work isn't OK in the long run, but talking about how I manage at school and so on, that's just fine.

The child is invited to give reflections on the happening by being asked: what do you think of that?

During the first interviews with the children, the topics *participation* and *decisions* came spontaneously as they related their experiences from consultations and everyday life. The verbs *to decide* and *to take part*/*to participate* are familiar words for children. For example one of the children explained that together with peers they participate and take decisions every day. I could therefore invite the child to reflect upon decision-making, and also to bring experiences of decision-making forward when they participate in consultations. For instance after talking about decision-making with friends I continued:

Interviewer: So what is to decide for you?

Child: Then I think about freedom, freedom to do what I want to do. Deciding what I want to do.

[…]

I: During consultations at the paediatric rehabilitation centre, what do you think taking part in decisions is about?

C: That they provide suggestions, which give me the opportunity to say what I want, or how I need assistance. They should listen to the child, listen to their view, ask 'Is it OK for you?'

I: How should children affect decisions being made by adults?

C: They should agree on what the decision is about, so the adults don't decide 'This is how we do it'. It's not OK if you're sitting there and don't say a word about it (how you want it to be).

Experiences that the children had about decision-making could be talked about in a concrete way by referring to what went on and by reflecting on the meaning of decision-making, thus making it easier to bring up the topic in the second interview.

Conducting interviews with children may not be so different from conducting them with adults. There is not necessarily a need for a specific set of methods to carry out research with children (Greene and Hill 2005, 8–12; Christensen and James 2008, 6–7), although the level of understanding, knowledge and interest must be considered (this must be done with all interviewees). Children may have problems understanding the meaning of a language filled with metaphors, and this should therefore be considered (Greene and Hill 2005), 10).

Critical comments on doing research with children, about how difficult it could be to get information from children and how it could be possible to ask children about decision-making, affected me when starting the interviewing. However, in the first interviews I met children who were talkative: they liked to talk about their experiences from the paediatric rehabilitation centre, which helped me. In addition, I found using the life mode interview helpful. Asking questions about what happened in a specific situation made the child decide what was relevant to talk about. Thereby questions concerning whether the child is too 'vulnerable' or too 'immature' to be asked certain questions became less prominent. The life mode interview emphasizes starting talking about concrete events and inviting reflection upon the experiences rather than asking general and/or decontextualized questions that can be

difficult to answer. Seeing the interview as a situation where the interviewee and interviewer interact and together produce knowledge acknowledges the reflexivity of the child/adult and the researcher during and after the interviews. The interview can also be seen as an event, where meaning and knowledge are produced. It is not a question of right and wrong or whether what the children relates can be trusted.

I experienced that some of my questions were misunderstood if I did not exemplify them with reference to what they had already told me about a specific happening. I had to get used to not asking general questions, even though I had prepared myself not to do so.

In addition, the power relations between the adult and the child must be taken into account since it is easy for adults to patronize children (Green and Hill 2005). Being an adult and a researcher may represent a power dimension, although it is difficult to know what the children interviewed in this research project thought about my status as an adult and as a researcher in the situation. Some of the children talked a lot and were relaxed, while others were quieter and did not have much to say. An important power dimension concerns whether the children were properly informed about the purpose of the interviews and the project. This was ensured by informing them and talking to them about the purpose of the project before the interviews. The children seemed to control the situation through how they chose to answer and reflect upon my questions. Some of the children chose to talk about friends and everyday life activities. Time was therefore spent talking about leisure time in order to make their stories about participation in everyday life activities with friends relevant to the last consultation. If happenings at the centre came up that the child did not want to talk about, I changed the subject.

Audio-tape and transcription

The interviews are audio-taped, and a question often addressed is if relevant information may be given once the audiotape is turned off (Warren 2001, 91). My experience is that the children did not tell me much more after the audio recorder was turned off. I wrote down relevant things that were said after the interview.

Three of the interviews were transcribed by a transcriber, and the other interviews were transcribed by me. The interviews were transcribed verbatim word for word. Pauses and expressions such as ‘hm’ and ‘eh’ were written down. Translating the interview material used in the articles from Norwegian to English was done in cooperation with a second person. The recorder may be a possible constraint on giving information, but I did not experience that they

started to talk more or give special information once I had turned off the recorder. Transcribing interviews is part of the analysis process (Kvale and Brinkman 2009, 177–187) since you notice different things happening – such as tone of voice, pauses etc.

Group interviews with the professionals

The six professionals participated in three group interviews. The interviews were carried out over a time span of two and a half years, during the same period as the observations and the interviews were conducted. The interviews were conducted at the paediatric rehabilitation centre.

A mix between asking questions of each participant in the group and presenting topics where they were invited to share reflections was utilized. The questions were about participation, decision-making, paediatric rehabilitation, the division of tasks between the professionals, reflections on being observed, topics such as children's participation, and discussions about the specialist healthcare services' responsibility in paediatric rehabilitation. In paper 1 the division of tasks between the professionals is made relevant. In paper 3 children's participation and decision-making is analysed and discussed.

Although questions and topics were prepared for the interview, the group interview had the character of being open-ended. The questions asked guided the conversation, answers were clarified and new questions were asked to pursue the implication to the main question and thereby to try to remain flexible and attentive to the variety of meaning that emerged during the situation (Warren 2001, 86–87). Questions on topics other than children's participation, such as the organization of the centre and the cooperation with the community healthcare services, were asked as a strategy to obtain information on contextual conditions.

The group interviews complemented the observations and the informal conversations, and the interviews with the children. In addition, during the group interviews it was possible to check whether my observations and reflections were recognizable and seemed plausible to them.

Some of the critiques to the use of group interviews are that a group interview can be difficult to control for the interviewer. The participants can be prevented from expressing their view because of asymmetrical power relations in the group and the possibility of leading questions (Morgan and Krueger 1993; Wilkinson 2004; Kvale and Brinkman 2009, 168–175). However, at the same time the group interview is considered to be well-suited for exploring new domains as it produces expressive and emotional views (Kvale and Brinkman 2009, 150).

As described earlier in the chapter, the asymmetrical power relations of the group concerns the relationship between the professionals and how I as a researcher/ interviewer position myself in the situation (Warren 2001, Holstein and Gubrium 2004). The professionals were interested in my preliminary findings, and they wanted some sort of feedback during the group interview. They also had reflections about how I considered their work, and I therefore found it reasonable to give them some of my reflections without evaluating their work in terms of right or wrong. I felt it was brave of them to let me observe their work, and in addition joining the research project was time-consuming for them. I considered disseminating reflections, regularities observed and preliminary findings from the analyses a way of accommodating their interest in what participation in the project could provide for them. By doing so I could check if they recognized my findings and if they found my interpretations reasonable. They did recognize my findings, and they followed my reflections and explanations, and they contributed with new reflections or corrections.

The interviews were audio-taped. They lasted between one and a half and two and a half hours. I wrote down my observations during the group interview and immediately after the interview. In addition I wrote down keywords under each topic or question being discussed. I had to go through the audiotapes several times. What I used from the group interviews was governed by the analyses of the observation and the interviews with the children. For example in paper 1 extracts from the interviews are used to complement the observation described in the article. In paper 3 extracts from the group interview where children's participation and decision-making was discussed were used. Listening to the audiotapes made it easier to memorize the actual situation and the interaction between the participants. I transcribed verbatim word for word the extracts that were relevant information for the topic being analysed or discussed.

Analysis and theoretical framework

In this part I will address the process of systematizing the empirical material and the process of choosing theoretical frameworks.

The process of analysing the material starts when gathering information by reflecting on the data gathered, and also by thinking how the data can be analysed by theoretical concepts.

Different theoretical concepts were used throughout the whole research process in a sensitive way (Blumer 1954). This entails using theory and concepts as a tool to interpret the data,

seeing how they fit, and evaluating if and how these concepts or theories can give explanations of the material. Blumer (1954) writes about sensitizing concepts:

> "It gives the user a general sense of reference and guidance in approaching empirical instances […]. Whereas definitive concepts provide prescriptions of what to see, sensitizing concepts merely suggests directions along which to look." (Blumer 1954, 7)

Using definitions was a useful strategy when sorting the material. For example I could systematize what the children had described according to how it reflected competence, autonomy and relationships with others, as defined by Ryan and Deci (2004, introduction). This helped me to see what the stories they told me were about. I view the use of concepts as a way of sorting the empirical findings, but they should be used critically. As a researcher I find it important to be open for the possibility that definitions of concepts do not fit the empirical findings.

Analysing the consultations: the use of Goffman and Latour/the Actor Network Theory

It was not until I had observed ten consultations that I started to systematize the consultations according to regularities, words and themes being repeated. For example, there are always conversations with the parents and the child, and measurements are taken during consultations. The doctors and the physiotherapist or the other professionals have tasks to perform. In addition, it is presumed that the child should play with the toys and equipment in the room. This is described in paper 1. Some of the interaction during consultations is routine, but each consultation is unique. Unexpected things can happen, and material aspects – such as the size of the room, toys, and equipment – affect the interaction at play.

I was recommended to reread Goffman's Interactional Rituals (1967) and to evaluate how his perspective could add to the exploration of the empirical material and the interaction at play during consultations. Parallel to this I attended seminars where materialistic approaches were discussed and where lectures were given on Bruno Latour's theories and the Actor Network Theory (ANT). I became more attentive to materialistic conditions, the use of objects and what was in the room. Two different perspectives inspired me: one in the tradition of the Chicago school inspired by symbolic interactionism, seeking to understand the socialization of social beings, the other was concerned with the material, entities and the specific, and being critical to the universal law guiding behaviour and sustaining social structure. Both

Goffman and Latour are concerned with construction in interaction: persons and meaning (Goffman) and knowledge (Latour) are formed and constructed through social interaction.

Throughout Goffman's work is the notion of role and focus on the individual actors. In his writings there is an interactive mix between the use of empirical description and his own interpretations of the social interaction by paying great attention to social categories. Goffman views categories such as 'deviant' as not useful in themselves as they do not exist before they are defined and studied by the researcher (Hacking 2004, 297). The reflexivity of the researcher and the use of theory are based on the social interaction at play. Even though Goffman was concerned with roles and expectations of roles, it should be mentioned that Goffman's writing is also about the variety of social interactions and the uncertainty of interaction.

However, Latour takes the uncertainty of action much further (2005). Latour is concerned with how things are not fixed but rather uncertain. To underline how interaction between people may be uncertain and does not follow a certain set of rules, Latour proposes to view action as dislocated and to pay attention to networks rather than groups (Latour 2005, 46). According to Latour (2005), there is no higher structure or explanation for what people do. Networks need to be repeatedly performed to be sustained as a network. Latour is concerned with the production of knowledge in interaction between people and objects, which is a critical project in itself, and not socialization as Goffman is. Latour is critical to models explaining what is happening because these models have a tendency to attract prior attention, thereby explaining those facets of social relations that suit the model. Latour uses the word *reassemble* and not *representation of* to escape the symbolic explanations. Agency is in flux, objects can be agents, and agency is important because it highlights what makes a difference and can reveal power relations. Latour is concerned with technology studies, and together with Callon and Law (Latour 2005, 10) he developed the Actor Network Theory (ANT).

ANT emphasizes the impact of non-human entities (objects) in interaction, and defines objects as actors to underline the importance of investigating how objects or material conditions affect how things are connected – for example in an encounter (Law and Hassard 1999). This inspired me to pay more attention to how the equipment, room and space were used. He traces how relations are connected, how objects facilitate action (inscription) and lead to a goal (translation) – for example a decision. Attention to this process of how relations

are connected emphasizes the specific actions, which makes a significant impact on the outcome.

Latour (2005, 133) considers the researcher's role during information gathering and the strategies the researcher takes as data in itself, and thereby emphasizes the close relationship between the researcher and the object of study. How objects and persons are linked opens up for seeing certain aspects, and may reveal actions that make a difference and affect the decisions being made. This is analysed and discussed in paper 1. In addition, how things are connected reveals 'findings' that may contest existing knowledge. In relation to children's participation, aspects of how they influence the situation can be easily overlooked if what the children do and how this action is recognized by the professionals is not considered. Latour's point is important for the present study as a consultation consists of expectations and a system may constrain opportunities. However unexpected actions happen in the encounter, which is part of the knowledge produced during a consultation. The role of objects is explored in paper1.

Nonetheless I was still left with unanswered questions to explain regularities such as routines and different tasks performed by the professionals and how these affect the encounter. Goffman's attention to the relationship between demeanour and deference in interactional rituals is used to analyse the encounter. By using Goffman I could explore the interaction between professionals, parents and children by paying attention to what the data material displayed regarding performance of roles. Deference and demeanour highlight two dimensions of courtesy that can be seen as either preventing or promoting children's participation. Goffman names the repetitive actions people do as rituals, and the actions are symbolic because they are meaningful to people. In addition, the interaction symbolizes a system in practice – in this case professional work in paediatric rehabilitation.

I was reflexive about the use of theory. Goffman explores the facets of self-perception and the perceptions of others in social interaction through the enactment of roles. What people do represents a system that guides people. People use different signs to inform the environment about their own social identity. Goffman's theories are criticized for not explaining how the structures or institutions guiding people's behaviour come into being (Hacking 2004), and for not paying enough attention to power relations (Shuttelworth and Kasnitz 2004). In addition, it may seem as if everything that is happening during a consultation can be explained by

understanding the actors as conscious, knowing what will happen in an encounter. This may not be the case, however, since regularities happen during a consultation and I found them relevant to explore according to Goffman's theory. Even though Goffman is concerned with how roles (and institutions) guide behaviour, meaning is constructed in the encounter, and the essence of being a person is constructed in interactions. Goffman's detailed writing describes many of the nuances in social interaction – for example distinguishing between deference and demeanour (paper 1), which is valuable when analysing the data.

Applying ANT and Latour's critical theorizing is interesting because the extensive notion of how things are in themselves, the particular, the unfixed aspects of social life, has great impact on contemporary research in the humanities and social sciences (for example Strathern 1996; Mol 2002; Moser 2006). Latour is criticized for not following up his methodological considerations in his own research (Asdal 2004)[3].

Analysing the interviews with the children: the theory of embodiment

Parallel with the work on paper 1, the work of systematizing and analysing the children's experiences from the interviews started. To make a distinction between the children's descriptions, the children's interpretations and the researcher's interpretations (Fangen 2010, 208–234; Green and Hill 2005; Haavind 2000), I wrote down what the children felt and thought about the consultations through their expressions. For example they could use words such as "like", "don't like", "boring", "scary", or "dreadful", "fun" or "OK." The children's experiences were seen in relation to these three concepts, and thereby what they emphasized. The children's stories differ, although they display similarities on the matter of how they wanted attention to their disability (body).

To analyse the material, reading disability studies and discussions on the medical and social model of disability made it clear how the relationship between disability and impairment was emphasized in the children's descriptions. However, the material described other conditions where the different definitions of disability were not sufficient. I was recommended to read the article written by Scheper-Hughes and Lock 'The Mindful Body - A Prolegomenon to Future Work in Medical Anthropology' (1987), which is still central to discussions concerning embodiment. The article suggests an analysis where experience is emphasized (children's experiences from attending consultations) to see what the related experiences

[3]More recently Latour is criticized in Aftenposten 21. October 2013 by Professor Jon Elster for putting doubt to the knowledge production in natural sciences.

reveal about social practice (professional practice), and also to analyse how the practice is guided by constraints or regularities – for example professionals' ideas of children's ability to understand, and medical practice, legacy or guidelines on how to practice paediatric rehabilitation. The theory is about what the body represents and what it is like being (with the body) in a society.

I worked on the children's descriptions again, and decided to choose some of the interviews about 'liking to go there (consultations)' and 'not liking to go there'. 'Not liking to go there' is experienced differently by the children, and I therefore selected one more of the interviews where not liking to go there is articulated as 'I dread going there'. Their descriptions are used and analysed in paper 2.

Research on embodiment is concerned with the body as physical and social, as explained in paper 2, but embodiment can be emphasized in different ways (Lock 1993; Lock and Farquhar 2007) – for example as personal and felt through movements or by paying attention to the body as cultural. Personal experience cannot be separated from the physical body, and what defines a body is socially constructed. What your body looks like, if the body is female or male, will affect how people relate to one another. What children with impairment experience in different contexts gives information on what their bodies are materialized with: being 'impaired' or being (dis)abled and how they think about this. It is thus possible to see the professionals' practice in a critical light. For example if a child says 'I want them to see that I feel normal', it points back at something the professionals do which makes them not feel 'normal'. The theoretical framework proposed by Scheper-Hughes and Lock differs from earlier notions of the body as social by adding attention to power and constraints (body politic) (Csordas 1994, 1–20). The framework has been imported in analysing the repression of people's bodies in different cultures – for example by considering the practices of organ donation across the world. The framework contributes to the field of critical ethnography.

Recent theorizing and studies on embodiment in the field of anthropology, which can be read as a critique of the model applied as a theoretical framework for analysing the material, go further in their argument about embodiment by saying that it is not question of representation but that the body is social in itself. These ideas are similar to the Actor Network Theory. What the body is believed to consist of is produced in the situation (Lambert and McDonald 2009), and attention to the production of knowledge in the situation is emphasized.

Embodiment may emphasize how society treats and understands people according to their bodies. To mention some examples, having a female body may in some societies exclude you from certain arenas, and being a person with impairment may exclude you from participating in activities because society is not concerned with physical adjustments. With regard to children's participation, I chose to keep to this analytical framework as it pays attention to how the children talk about their body and experience their body as being seen by others. Working on the interviews with the children and writing paper 2 gave rise to paper 3.

Analysing children's experiences and professionals' experiences as stories

Working on paper 2 and analysing the interviews with the children, I wanted to address the decision-making processes and the children's own view on participating in decision-making, as well as the professionals' views on children's active participation in decision-making. I wanted to use more of the material from the group interviews where the professionals talked about children's involvement in decision-making. Narrative forms of inquiry have been visible in both childhood studies and disability studies (Hanisch 2013;Hunter and Eder 2010; Smith and Sparkes 2007; Ulvik 2007), and I started to explore how I could solve an analysis of the professionals and the children's views on decisions making. I was inspired by Gubrium and Holstein 'Analyzing narrative reality' (2009), and by attending a seminar where Gubrium held a lecture.

Gubrium and Holstein see the interview as a happening in itself, where the story being told is a product of the storyteller (the interviewee) and the listener (the interviewer) and how stories are produced. Meaning making of the story through 'linkage' is crucial (described in paper 3), and what this can reveal about the status of the persons involved in the story. Gubrium and Holstein's theory and analytical framework is different from that of Goffman, but at the same time complements Goffman by emphasizing roles, status and the lived experience of persons in encounters. Although in narrative analyses the attention is often on what the story is about, Gubrium and Holstein (2009) emphasize both how stories are produced and their content. Parallel with this I started to read Arthur Frank 'The wounded story teller' (1995), and I found Frank's categorizations of narratives about illness inspiring and interesting to apply to the empirical material. I decided that I wanted to put emphasis on Frank's theory (described in paper 3) and on the analytical concept of 'linkage' from Gubrium and Holstein (2009).

I started to analyse how the professionals describe working with children's participation in decision-making. I focused on how the professionals described participation to reveal the

meaning making of children as active participants in decision-making. I analysed how the children described decision-making in the interviews. I wanted the professionals' voice to be more central in this article than the others, and at the same time to pay attention to the children's stories. I wanted the children's stories to be used as a comparison to those of the professionals.

Frank makes the point that each story has a testimony to tell, and the research project that I am part of argues for listening to children's voices. I decided that I wanted to present one of the children's stories and to use this story as a 'comment' to the professionals' descriptions. According to the professionals, decisions on surgery and involving children in this process is a difficult topic, and this girl's story about her experience from not being involved in the decision-making process on surgery was therefore selected and applied in paper 3. I also found it reasonable to use one child's experiences to demonstrate how one child's views could highlight and give insights into the professionals' understanding of children's participation.

Attention to life stories and experiences and to analysing them as narratives can be seen as part of a postmodern project where reflexivity, attention to emotions and the importance of storytelling in itself (Frank 1995, 4–7; Smith and Sparkes 2007; Thomas 2010) are emphasized. Frank points out that during past decades illness has become to feel different, and this is postmodernity. The modern experience of illness begins when popular experiences are overtaken by technical expertise, including complex organizations of treatment. Frank (1995) writes:

> "The story of illness that trumps all others in the modern period is the medical narrative. The story told by the physician becomes the one against which others are ultimately judged true or false, useful or not."(p. 5)

Postmodern narratives pay attention to the patients' stories, and medicine needs these stories because they have a testimony to tell.

Frank's theories and research project is reflexive in the sense that the emphasis is on the individual becoming self-reflexive by telling and listening to stories. Frank's writing has the character of being auto-ethnographic as he brings his own experiences into the text. Frank uses his own experiences and places himself among the standpoint theories where his analytical standpoint is rooted in solidarity and sensitivity towards those who are struggling with illness.

There are critical voices to the narrative project. For instance Atkinson (2010) has questioned if narratives guarantee the real, the authentic and the inner self descriptions. All knowledge is produced, and thereby narratives are not more authentic than any other method of acquiring knowledge. Atkinson also criticizes Frank's book 'The Wounded Storyteller' for its lack of social context, action and interaction, and because there is too much personal commitment and too many assertions (Atkinson 2010, 661–667). A counter-claim is that Atkinson favours the analyst over the story but does not recognize how the analyst affects the story. Another element is that Frank's theorization does not take into account disability. However, Frank emphasizes that listening to others' stories is an ethical project: stories work for others and medicine needs this story. Paper 3 is an argument for using children's experiences and their stories as a way to highlight paediatric practice and professionals' experiences. In addition, paying attention to the meaning making of stories and what the stories are about provokes a discussion of the complexity of children's participation in paediatric rehabilitation in particular, and of their participation in general.

Together, these social theoretical frameworks emphasize important perspectives for exploring what children's participation is about: the encounters (roles, statuses, positions and materiality), the embodied experience and the stories of these interactions and experiences.

Dissemination of findings

As already described, the interviews, the group interviews with the professionals and the informal conversations with the professionals worked as situations where I could discuss preliminary findings and possible interpretations. In addition, I presented findings at conferences and seminars where professionals from the centre where I conducted the research and other professionals from other hospitals working in paediatric rehabilitation participated. I also presented findings at conferences where children with disabilities participated. At seminars for the professionals working at the centre I conducted my research, the professionals gave responses to the recognizability, although at the same time listeners said they were not used to the detailed descriptions that put experiences into words.

Discussing generalizability in the distributional sense will not provide much information (Peräkylä 2004, 295–300). However, the findings have some wider relevance: there is a premise that there is something general in the specific and vice versa. Findings from conducting research at one centre in the paediatric rehabilitation system may have relevance for other centres as well. The national (re)habilitation system forms the basis for specific

situations to be recognizable and to contribute relevant information on and for paediatric rehabilitation practice.

The three articles and this thesis maintain that the findings and the discussions have relevance for children more generally and for professional groups other than healthcare professionals working with children. However, it is up to the reader to make that judgement.

Limitations of the study

The study emphasizes the different experiences and what experience can contain. Even though the descriptions represent a context that is recognizable for others and points to topics that have relevance for other groups, the study does not give information on how children in Norway experience attending consultations. These are only some examples. Choosing an in-depth study of the qualitative material implies that only a small amount of the material is presented in publication. The whole range of data is only used in the process of analysing the material. A limitation to this may be that there are many examples or a large amount of data that is not explicitly highlighted, and it might be difficult for the participants in the research project to see the value of their own contribution. Another limitation when choosing qualitative interviews as a method is that it can be hard to find children who are willing to participate. Children and parents who have negative experiences may be anxious about telling their stories to an interviewer. Participants volunteering for research projects may also be families who are resource persons. In addition it is time-consuming to participate, and for some it might have been easier to fill in a questionnaire rather than meeting a researcher.

Chapter 4: Ethical considerations

In this chapter I will discuss consent and choice, as well as confidentiality. This chapter should be read as an extension of the previous chapter (3). This chapter adds to this discussion by underlining facets related to choice, consent and confidentiality. Consent concerns informing the participants about the research project, and about the risks and benefits from participating in the project. Consent involves obtaining voluntary participation and the possibility to withdraw from the study at any time (Kvale 2009: 70) Confidentiality concerns the implication that private data identifying research subjects will not be disclosed (Kvale 2009, 72; Fangen 2010, 272).

The professionals

Consent and choice

According to Regional Committees for medicine and health research ethics (REK 2009), the participants' consent must be seen in relation to the purpose of the research. Conducting observation is a strategy for acquiring information about professional work, scarcely documented in research (chapter one). How the professionals at the paediatric rehabilitation centre were informed about the research project, and how the main participants volunteered, is described in the previous chapter under recruitment (pp. 27–28). There were other participants involved in the project besides the main participants: the leaders of the rehabilitation centre took the decisions on accepting to participate in the research project. This meant that potentially all the professionals at the centre could be observed if they were present during consultations that I attended. Other professionals had to consent orally to my presence. If they did not consent, I could not participate in the consultation. They were asked before I was scheduled, so I do not know if anyone did not consent, and they did not have to worry about my knowing.

The families coming to consultations had to consent to my presence. Even though they were informed days before the consultation, the professionals spent time with the children before the consultation to be sure they were informed. The children had to agree again before we entered the room together. There is always a chance that the child and the parents say yes because they feel they have to. Therefore I paid attention to behaviour that might indicate resistance to my presence. For example in one consultation the family had given consent but the child was afraid and anxious about the electrode being attached to the head, and if it

would hurt and be harming, and the mother tried her best to ease the situation for the child. The mother seemed somewhat stressed by my presence. I decided on agreement with the nurse and the mother to leave the room and to continue the observation behind the mirror window in the other room.

The professionals could withdraw from the study at any time if they wanted to. None of them withdrew.

Confidentiality

The place where the research was conducted is kept anonymous and is not revealed in published documents or in presentations. Professionals working at the paediatric rehabilitation unit are anonymous. Pseudonyms are used and genders are mixed.

There is always the potential for being recognized in qualitative research with few informants in a local setting (Kvale and Brinkman 2009, 272). The professionals at the centre can recognize the other professionals working there. They are aware of this, and took it into consideration when volunteering. These conditions were discussed before volunteering for the project. The names of the other participants during consultations are not given, and information is not provided on the child's diagnosis in publications.

The children

According Regional Committees for medicine and health research ethics (REK 2012), consent, harms and benefit from the research and confidentiality should be considered.

Consent and choice

As already explained, the children were recruited through the paediatric rehabilitation centre. Since the children are under the age of 18, their parents have to consent on behalf of the children. The children in this study were between the ages of 10 (in the year of recruitment) and 15 when they gave their first consent to participate as interviewees. They were informed about the project by their parents through two different information letters, one of them written in a non-academic language. According to the Helsinki declaration (WMA 2008) careful consideration must be given to children defined as especially vulnerable – including children with disabilities. The children who volunteered to participate are not diagnosed with cognitive disability. Knowledge of their age and individual needs is the main factor to consider (Alderson 2005, 27–37).

For the oldest participants who volunteered, their parents said that they felt it somewhat superfluous to arrange an appointment and talk to me on behalf of their child. The oldest,

aged 14, understood what participation in the project was about. For the youngest nine- to eleven-year-olds, I spent some time talking to them before we started the interviews (the first and second times). Even if some of the children did not see their experiences as very special, they were proud to contribute information. During the interviews with the children questions concerning their private family life were not asked. If a child experienced it as exhausting to talk about negative experiences, I changed the subject. Before the interviews they were told that they could withdraw from the study if they no longer wanted to participate.

The children interviewed could withdraw from the study at any time if they wanted to. None of the children withdrew. Before the second interview we talked about the purpose of the research project and whether they still wanted to be part of the study. Before the second interview I also talked to the parents to find out if it was acceptable that I interviewed again.

Confidentiality

The professionals working at the centre do not know who were sent invitations to participate in the research project. Nor do the professionals know who accepted the invitations. The children are anonymous and are presented with pseudonyms in the papers. Exact age is not given. I was not informed about the children's diagnoses, and do not have access to the children's filed journals. Ethnicity is not described in the publications or in other results being presented. All I know about the children is what they told me during the interview.

Being cautious about confidentiality was guiding me when choosing extracts from the interviews. There may be a possibility that the children will be rather anxious about whether the professionals will recognize their story. However, a high number of children attend consultations at the centre per year, and it is difficult for the professionals to recognize them. Nonetheless, the information the children give represents important feedback for the professionals if they want to improve their work on involving children in decision-making processes.

Balancing the harms and benefits of this research project, it is easy to see that the professionals benefit from participating in the project. Any probability that the project will harm the children is difficult to find. The immediate benefit is the feeling of gaining self-esteem, which may be a crucial motivator. By participating in the project, one of the children became inspired to share more of her experiences with others.

Chapter 5: Main findings

Summary of papers

Paper 1
The role of objects in understanding children's participation in paediatric rehabilitation

In paper 1 the interaction between the participants during a consultation is analysed in order to demonstrate how children's participation can be seen. Each encounter between children, professionals and parents is distinct, and during a consultation the child participates in different ways. However, routines and actions are performed in most of the consultations: taking measurements, conversations, and exploration and play by the child with objects and equipment in the room. How the child participates and how the child's participation is taken notice of during a consultation is explored in paper 1.

The boy in paper 1 is not actively involved in the conversations during the consultation, even though he often interrupts in different ways in what the adults say. The boy's interruptions and objections are not further explored by inviting the boy to tell more about his opinions. The parent excuses and tries to stop the boy's interruptions. While the conversation goes on between the adults, the boy explores the objects in the room and plays with them. The physiotherapist alternates between playing with the boy and listening to the adults' conversation.

After the consultation the professionals meet for a summary meeting and to decide interventions for the boy. The discussion reveals that all the professionals have taken notice of how the boy explored the room and used the objects in the room in a creative way, and they found the noise and interruptions positive. They regarded the interruptions and objections as information relevant for deciding interventions rather than as improper behaviour – as they understood that the mother interpreted it to be. The professionals' positive opinion about the boy's interruptions and objections was not expressed to the mother during the consultation.

The analysis reveals that there is lack of common understanding among the professionals, the parent and the child about what will happen during the consultation. In this case the boy's exploration of the objects in the room counted as positive when the professionals decided on interventions for the boy. However, many things about the boy were not explored, which could have affected the decision-making process. In addition, this case demonstrates the

importance of materiality during consultations since it can open up for an exploration of who the child is.

Paper 2

"I want them to see that I feel normal."

Three children's experiences from attending consultations in paediatric rehabilitation

Three children's experiences of taking part in consultations are explored in paper 2. Two of the children do not like going to the paediatric rehabilitation centre for consultations, and one likes going there.

The child who likes going to the paediatric rehabilitation centre likes it because he can then demonstrate that his physical capability is still good even though he has a progressive impairment. Therefore it is important for him to demonstrate his skills and physical strength to the professionals. He also wants the professionals to pay attention to everyday life activities and to how he experiences functioning in activities and together with his peers. It is important that the professionals pay attention to how he manages to live with the disability – not only to his impairment.

One of the two children who do not like to go to the rehabilitation unit dislikes it because she thinks the professionals focus too much on the impairment and her disabilities rather than on experiences from everyday life activities. The girl does not experience herself as very different from her peers even though she is disabled in many situations. It is important for her that the professionals accept and acknowledge her experiences. For her, too much attention to her impairment is challenging because it affects her self-perception of being a 'normal' girl.

The other child who does not like going to the rehabilitation centre does not like it because he feels excluded from taking part in decision-making concerning his own rehabilitation programme. He felt that he did not have any control over the rehabilitation programme that was planned for him after surgery. He found the training programme very exhausting and demanding, and in addition he had experienced being placed in another room when the adults discussed decisions about him. He therefore became anxious and thought the professionals did not care about him. Because he felt it very problematic to go to the centre for check-ups, the professionals changed their focus and started to make him an active party in the planning of his own rehabilitation. This decreased his negative feelings about going to the centre, but he still dreads going there.

The children tell stories that reveal a professional practice where physical impairment is given considerable attention. The professional practice is guided by medical rehabilitation practice, and a practice of not involving children in decision-making processes. The analyses demonstrate the importance of talking to the children about their experiences to find out how they want the attention given to impairment or disability to be.

Paper 3

Children in Pediatric Rehabilitation Decision-making

Professionals' Experiences vs. Children's Views on Decision-Making Involvement

This paper explores how professionals' experience children's participation in decision-making processes. The professionals describe that it is more difficult to involve children in decisions about medical interventions such as orthopaedic surgery than in decisions about social intervention related to the child's everyday life activities. When orthopaedic surgery is discussed as a possible intervention, the child's own view is given less attention. The professionals emphasize that medical intervention also often gets priority before discussing social intervention where the child can talk about needs and experiences from everyday life. The professionals also describe high expectations from parents about improvements for their child through the use of medical interventions. In addition, the professionals have expectations of themselves about fulfilling a professional role based on medical practice. The professionals underline that attention to strategies for the child concerning how to live with the disability in everyday life are often more important than medical interventions such as surgery.

The professionals' experiences are compared to a girl's story about not being involved in the decision-making process on surgery. The comparison of the child's story and the professionals' stories reveal that the professionals have an unclear understanding of the child as an active participant in decision-making processes. The child on the other hand sees herself as a natural part of decision-making processes concerning her own life, since lack of involvement will produce feelings of insecurity and anxiety about what will happen to her. Her statement about the need for others to listen to children's views in decision-making, no matter the age of the child, is shared by the other children interviewed in the research project. To be involved in decisions is not the same as taking the final decision.

Chapter 6: Discussion

This final chapter will start with a brief summary of the main findings. I will then discuss some implications that the research findings may have for paediatric rehabilitation practice and for research on children's participation.

The research project has been conducted on the basis of the need for in-depth information on how children describe participation in paediatric rehabilitation consultations, and how professionals work with children.

Children's participation in decision-making in paediatric rehabilitation is very much dependent on how the professionals communicate their roles and on the extent to which they invite the parents and the child to give their opinions and share experiences. In addition, the extent to which the professionals explore the child's actions during consultations is crucial if children are to become active participants in decision-making processes.

Seen from the professionals' perspectives, the study reveals that children's status as active participants in decisions about their own rehabilitation is unclear. Seen from the children's perspective, children should be viewed as active participants to avoid them becoming vulnerable. Information given to the parents and the child and clarity from the professionals about what will happen during a consultation are crucial for the child's participation and involvement in decision-making. The professionals say they have positive experience of involving children in decision-making, although these experiences receive little attention among the professional groups working at the centre.

The professionals keep to medical interventions when evaluating the children, even though they are not always convinced that this is the right perspective to put emphasis on in some cases. The children being interviewed in the research project want more focus on their (dis)abilities in everyday life than on physical impairment. They want the professionals to accept and acknowledge them as being in many ways like other children.

Implications for practice

In this section I would like to discuss the findings in relation to the definition of habilitation and rehabilitation and the regulations on habilitation and rehabilitation.

Paediatric rehabilitation and rehabilitation is defined as follows:

> "Habilitation and rehabilitation are timed and planned processes with clear goals and means, where several parties cooperate in providing necessary support to the patient or user's own efforts to achieve optimal functional and coping skills, independence and participation in everyday social life and in society." (Regulations on habilitation and rehabilitation 2011[4])

The definition emphasizes cooperation and measures to achieve independence and participation socially and in the community. In chapter 2 of this thesis it was mentioned that it is essential that contemporary rehabilitation perspectives such as 'cooperation' and 'the individual's overall needs' are brought into the different rehabilitation practices. Cooperation and overall needs will be emphasized below.

The new health legislation assigns great priority to cooperation on the total needs of the individual (Directorate of Health 2012)[5]. The person's overall needs is the person's psychological, social and medical needs. The specialist healthcare service is responsible for medical measurements and tests as a means to define the patient's (re)habilitation needs. The specialist healthcare service complements the community service with specialized competence – for example neuropsychological tests and special tests for measuring motor function. They are also responsible for bringing in specialists on orthopaedic surgery to evaluate the child's need for surgery (Directorate of Health 2012[6]). Medical intervention is crucial in paediatric rehabilitation and can be explained in the organization and in the allocation of tasks in the services. Medical intervention is not problematic in itself; however, as this research study demonstrates, an exploration of the social and psychological needs of the child receives little attention if the focus is on the medical part of rehabilitation.

To make cooperation and the child's overall needs an active part of paediatric rehabilitation implies that the professionals need to integrate and evaluate these two conditions together with the medical interventions. When the official documents emphasize psychosocial and social rehabilitation in addition to medical rehabilitation, this can be read as an acknowledgement of these facets of (re)habilitation. This may open for more attention to the patient's own experiences, but still needs to be emphasized even more, especially when it

[4]My translation of: Habilitering og rehabilitering er tidsavgrensede, planlagte prosesser med klare mål og virkemidler, hvor flere aktører samarbeider om å gi nødvendig bistand til pasientens og brukerens egen innsats for å oppnå best mulig funksjons- og mestringsevne, selvstendighet og deltakelse sosialt og i samfunnet (Forskrift om habilitering og rehabilitering 2011).
[5]Helsedirektoratet 2012
[6]Helsedirektoratet 2012

comes to children. It is crucial to see the child as a person, not only as a disabled person. Slettebø (2012) also emphasizes that professionals take responsibility and that the patient is given responsibility. For the professional it is especially important to be aware of the responsibility they have for parts of the patient's life, and of the power that resides in this responsibility (2012, 115–116). This applies for professionals working with children as well. The professionals in the study underline the importance of sharing the positive experiences professionals have from involving children in decision-making processes.

The aspects mentioned in this section are possible practices for improving professional practice that can be justified in regulations, guidelines and strategy documents.

The emphasis on the social and psychosocial dimensions of (re)habilitation together make an argument for paying attention to the individual's, including children's, own experiences in order to take measures that represent the person's total needs. If children are not involved in the decision-making process, if children are not listened to, and if the professionals do not act upon the children's views during consultations, does this reinforce the child as disabled? It is a provoking question, but may be crucial to ask. If being excluded from participating in decisions concerning one's own life is oppression (Morris 2001 and Thomas 1999), children may experience being disabled by the professionals. Viewing the consultations as one arena among many where the child participates, it is relevant to ask if this arena reinforces the child's own perception of being a person with ability or disability.

Moreover, the power that resides in the hierarchical structure of the paediatric rehabilitation services should not be underestimated. Words such as specialists, medical expertise, complexity and advice are used frequently for the specialist services. The system gives professionals an opportunity to take decisions as experts and to define what is best for the child, to inform them or not, to involve them or not in decisions.

Stiker (1999, 151–160) underlines that rehabilitation (and paediatric rehabilitation) is an arrangement for a specific group of people, which is a means of supporting those with rehabilitation needs to live as 'normal' a life as possible. Malterud and Solvang (2005) point out that society values independency and conformity, and those who are dependent on others or deviate from the 'normal' run the risk of being marginalized. Paying attention to children's experiences reveals how the child thinks of one's own experience of being 'normal' in relation to the professionals. Information from the children describing professional practice as challenging their own experience of being 'normal' is crucial information. One goal of

paediatric rehabilitation is to support the child in living a life that not only seems normal to others but is also experienced as normal by the person him/herself. The child's utterances and emphasis on being 'normal' may relate to his or her particular life situation. However, it may be crucial to see these utterances as vital feedback for the professionals, and in addition to relate it to the vocabulary that the professionals apply in practice and in relation to the child. As described in chapter 2, bodies or impairment in paediatrics are measured as atypical-typical, and there are many good reasons for not applying the distinction normal-abnormal in this context. However, it is how the professionals communicate with the children, and the words used together with the children, that affect the child's self-perception of being 'normal' or not. It is only the children themselves who can describe when or how they feel 'normal'.

The research findings emphasize that it is difficult for the professionals to involve the children in decisions concerning medical surgery. The child is seen as vulnerable when it comes to decisions on medical surgery, and the parents take the decisions for the child. However it can be repeated that children not being involved in many of the other decisions taken during consultations is not because the child is seen as vulnerable but because parents are used as proxies for the child. Parents do not necessarily have the 'right' understanding of the child's disability (Hanisch 2013). Not being involved in decisions, and the negative feelings and thoughts this produces in the child, is described in two of the papers of this thesis. Being excluded from decisions and not being informed about what is decided for them makes the children vulnerable.

To summarize this part of the discussion I would like to bring the emphasis of Fitzgerald et al. (2010) on *participation as a struggle over recognition* into the discussion again. They emphasize the dialogue – new possibilities and challenges for children's participation:

> "Conceptualising participation as a struggle over recognition is also useful because it focuses on participation as negotiated space that is dialogical rather than monological in nature ….To speak of children's participation as a struggle over recognition suggest that we must commit to a deeper consciousness of what it is that we seek through their participation and be prepared to recognise and act on it when we invite them into a participatory space." (Fitzgerald et al. 2010, 294 and 302)

There are challenges concerning children's participation in paediatric rehabilitation practice. Two of them are time and technology. Many children with disabilities who are enrolled into

rehabilitation programmes have speech difficulties, and both time and technology are necessary to enable these children to express their view.

Even though there are challenges, there are possibilities in the contemporary practice of paediatric rehabilitation as well, and the regulations on habilitation and rehabilitation provide guidelines that call for more attention to participation where children and adults together can 'struggle' over what is relevant in decision-making.

In the following I will address this research project's implications for further research.

Implications for research

The children in this study use their experiences to describe and evaluate their role as active participants in decision-making processes. The professionals use different perspectives, academic and experience-based, when describing the child as an active participant in these processes. During consultations the child's need for medical rehabilitations comes into the foreground. Throughout this thesis, attention is given to the perspectives that professionals and children bring with them into the paediatric consultation. This can be emphasized even more clearly in further research. Erica Burman (2008) suggests placing more explicit emphasis on the perspectives brought into different situations, in addition to making practices and experience is relevant: "We need to look at the interface between different groups of actors (parents, professionals, children […]), and work to document the varying and contested accounts of what particular interventions mean and what they achieve" (Burman 2003, 42). If the argument for listening to children is to become mandatory in situations where decisions concerning the children's own life are taken, more information is needed on the perspectives the participants bring with them into the consultations. Even though the choice was made not to interview the parents in this study, it is appropriate in future research to investigate the kind of perspective and understandings of disability (and childhood) parents bring with them into consultations.

The next factor I would like to emphasize that may have relevance for research is how to strengthen the child's right to be heard in paediatric rehabilitation. User involvement for adults in rehabilitation is clearly stated. This is not the case for children, and it is pertinent to look to the appropriate regulations such as the UN Convention on the Rights of the Child (UNCRC), and the UN Convention on the Rights of Persons with Disabilities (UNCRPD) (Article 7), where it is explicitly stated that children have the right to be heard in matters concerning their own life. It will probably be necessary to work on the relationship of the

regulations on habilitation and rehabilitation, on patient and user rights and with the UNCRPD Article 7 and the UNCRC Article 12. Since Norway has ratified the UNCRPD, it may be considered in relation to society's goal for paediatric rehabilitation. In addition, it may be useful if the legislation concerning children's rights could be applied actively in healthcare decisions as well, as Sandberg (2009) proposes. It should not be underestimated that the relationship between legislation and the child's right to be heard in paediatric rehabilitation affects whether children with disabilities are listened to or not in decision-making processes. Some parts of the existing regulations on habilitation and rehabilitation justify paying more attention to children's participation in paediatric rehabilitation.

This research project exemplifies the importance of letting children participate in research. It is often those with the most adult-like behaviour who are viewed as suitable to take decisions and to participate in research (Carter 2009). Disabled children are underrepresented in childhood studies (Cuskelly 2005; Tisdal 2012; Watson 2012). Children with cognitive disability in particular are often excluded from participating in research studies (Tisdal 2012, Davis et al. 2008). Although children's rights to be listened to have been promoted and improved through political processes, there is still room for improvements for children with disabilities. Children (with or without disabilities) may be excluded from research because they are regarded as not suitable or too vulnerable (Cuskelly 2005). What constitutes vulnerability is a central question. Vulnerability can be viewed as produced in relation to others and not as an innate capacity in the child. Children with multi-impairments and cognitive disabilities must also be heard if we are to cover the complexity of participation in paediatric rehabilitation.

Another implication for research is how the research project has complemented the contemporary research on children's participation. The research project explores children's participation and emphasises experience in relation to the context and the conditions that affect professional practice. The experiences are understood as situated in the context of paediatric rehabilitation. Paying attention to children's experiences and exploring professional practice make it possible to elucidate where adults exercise power to prevent the child being listened to. It highlights the importance of in-depth analyses to reveal the complexity of a theme. Why participation is crucial in specific situations needs to be asked to the children themselves. One barrier for participation in social interaction can be tacit knowledge, and conducting participant observation in the arenas where the interaction takes place may be useful.

The status of the children as active participants is revealed as unclear from analyses of the professionals' experiences. This underlines the importance of paying attention to experiences of practice. Berry Mayall (2000) says: "It is through working towards better understanding of the social condition of childhood that we can provide a firm basis for working towards implementation of their rights" (2000, 243). The paediatric rehabilitation consultation is one of the arenas where their rights can be strengthened.

Children's participation in paediatric rehabilitation has its own complexity. Theoretical perspectives emphasizing different aspects of experiences and social interaction are applied to explore children's participation during consultations. Doing this can be seen as a way to explore how different perspectives give new insight into the research topic. I believe children's participation is best understood through exploring how it is revealed in practice, and how it is experienced and told by the children themselves.

Throughout this thesis there is an argument for listening to children. Children cannot participate in decisions concerning their own life if they are not given a voice, and if their opinions are not acted upon. To involve children in decision-making in paediatric rehabilitation does not mean that they necessarily take the final decision, but it makes them active participants.

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Paper 1

Paper 2

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Paper 3

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Appendix

“Barn med funksjonshemning og deltakelse i egen habilitering i spesialisthelsetjenesten”

Hei

Jeg heter Wenche Bekken og arbeider ved Høgskolen Oslo som forsker. Jeg ønsker å snakke med deg om hvordan du som barn opplever det å komme til habiliteringsavdelingen og møte og snakke med de som arbeider der. Jeg vil snakke med flere barn som har vært flere ganger på en habiliteringsavdeling fordi vi vet for lite om hvordan barn og unge tenker og opplever disse møtene. Jeg ønsker å lære mer om dette fordi det er viktig for alle oss som arbeider med barn og unge.

Hva vil jeg gjøre?

- Snakke med ca. 20 barn i alderen fra 10-15 år som har erfaring fra en barnehabiliteringsavdeling. Dette vil skje to ganger og hver samtale vil vare i ca. 1,5 time.

Hva vil jeg snakke med deg om?

- Hvordan du har opplevd de gangene du har vært på barnehabiliteringsavdelingen.
- Litt om hvordan hverdagen din er, hva du gjør til daglig for eksempel.
- Hvordan du opplever å være med i forskjellige aktiviteter på skolen, i fritiden og hjemme.

Hvorfor?

- For å lære mer om hvordan barn og unge selv tenker om det å delta i egen habilitering.

Har du spørsmål så ta kontakt med (…) på tlf. 00 00 00 00

Forespørsel om deltakelse i forskningsprosjektet

"Barn med funksjonshemning og deltakelse i egen habilitering i spesialisthelsetjenesten"

Bakgrunn og hensikt
Dette er en forespørsel til deg på vegne av ditt barn om å delta i en forskningsstudie igangsatt for å få kunnskap om hvilke erfaringer barn har om medvirkning og deltakelse fra barnehabiliteringstjenesten. Barn og unge med erfaring fra habiliteringstjenesten i (…)mellom 10 og 15 år, vil bli spurt om å delta i denne studien. En annen del av forskningsprosjektet er å se på hvordan fysioterapeuter, leger og andre i barnehabiliteringstjenesten jobber for få barn delaktig i beslutninger som tas om dem. Et mål med studien er å styrke barns deltakelse i beslutninger som omhandler dem. Høgskolen i Oslo, avdeling for helsefag står bak studien, og vi vil samarbeide med barnehabiliteringstjenesten (…) for å få det gjennomført.

Hva innebærer studien?
Å være deltaker i denne studien innebærer å bli intervjuet to ganger. Hvis det er behov for det, kan det være nødvendig med en samtale i tillegg til dette. Intervjuene vil vare i ca. 1,5 time. Det ene intervjuet vil fokusere på hva barnet gjør til daglig, hvilke aktiviteter hun/han driver med, og hvordan hun/han opplever å ta del i de tingene som skjer til daglig. Det andre intervjuet vil fokusere på erfaringer fra barnehabiliteringstjenesten. Hvis det er behov, vil foreldre/foresatte måtte bidra med tilleggsinformasjon, som for eksempel spesifisere som når dere kom i kontakt med habiliteringsavdelingen for første gang. I denne studien er det i hovedsak barnas erfaring vi er ute etter å få kunnskap om, ikke foreldrenes da dette er belyst i tidligere forskning.

Mulige fordeler og ulemper
I løpet av perioden fra høsten 2010- våren 2012 vil barnet bli intervjuet. Intervjuene vil som nevnt ovenfor handle om hva hun/han gjør til daglig, og erfaringer fra barnehabiliteringssenteret. Intervjuene vil skje hjemme hos dere, eller på Høgskolen i Oslo hvis dere heller ønsker det. Hvis dere ønsker å være tilstede, så kan dere det. Intervjuene vil vare ca. 1,5 time, men vi kan ta pauser eller stykke de opp hvis det er ønskelig. Ved å være med i denne undersøkelsen blir barnet gitt mulighet til å fortelle om sine erfaringer som vil være til hjelp i arbeidet med å forbedre tilbudet for barn som er brukere av habiliteringstjenesten.

Hva skjer med informasjonen som barnet gir?
I tillegg til det barnet gir oss av informasjon om erfaringer og hva barnet driver med til daglig, vil vi få informasjon fra barnehabiliteringssenteret om diagnose og funksjonsvurdering. Dette har med avgrensingen for hvem som blir forespurt om å delta i studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode vil knytte barnet til opplysningene.

Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deltakerne. Det vil kun være forsker som vil behandle denne dataen, andre vil ikke få vite hvem som takker ja til å delta i studien. Opplysningene vil bli oppbevart innelåst i et arkiv.

Utover at barnet selv kanskje vil kjenne igjen det hun/han selv har sagt vil det ikke være mulig å identifisere barnet i resultatene av studien når disse publiseres.

Frivillig deltakelse
Det er frivillig å delta i studien. Dere kan når som helst og uten å oppgi noen grunn trekke samtykket til å delta i studien. Dersom dere ønsker å delta og barnet er enig, undertegner dere samtykkeerklæringen på siste side. Dersom dere eller barnet senere ønsker å trekke dere eller har spørsmål til studien, kan dere kontakte Wenche Bekken på telefon 22 45 25 18/00 00 00 00.

Ytterligere informasjon om studien finnes i kapittel *A* – *utdypende forklaring av hva studien innebærer.*
Ytterligere informasjon om personvern og forsikring finnes i kapittel B – *Personvern, økonomi og forsikring.*

Samtykkeerklæring følger etter kapittel B.

Virker dette interessent og dere ønsker at barnet deres deltar i denne studien ber vi om at dere sender inn underskrevet samtykke i svarkonvolutten som ligger vedlagt **innen -----**

Vennlig hilsen

Wenche Bekken
Stipendiat, rehabilitering- masterstudium
Høgskolen i Oslo

Kapittel A- utdypende forklaring av hva studien innebærer

Kriterier for deltakelse:

- Barn med erfaring fra barnehabiliteringstjeneste ved (…).
- Barn i alderen fra 10- 15 år som har diagnosen ryggmargsbrokk eller cerebral parese, uten alvorlige kognitive vansker.
- Barn som oppfyller kriteriene over, plukkes tilfeldig ut av adresselisten av habiliteringsavdelingen. Ønsket er å få 20 barn til intervju.
- Forespørsel sendes ut fra habiliteringssenteret, og deltakere som ønsker å delta tar kontakt med prosjektleder.

Bakgrunn for studien:

Statens helsetilsyn konkluderer i sin rapport "Ikke likeverdig habiliteringstjenester til barn" (2007), at det er brudd på retten til informasjon og medvirkning. Forskning gjort i Sverige (Bolin et.al 2003) viser at barn med funksjonshemning i liten grad kan forklare hvorfor de gjør som de gjør i en habiliteringsprosess, bare hva de gjør. Vi vet fra annen forskning og dokumentasjonsarbeid gjort i skolen at barn med nedsatt funksjonsevne opplever det meningsfullt å være deltakende, men at det varierer hvor deltakende de er i planleggingsprosesser (Asbjørnslett 2005, Assistanse 2009, NHF Oslo 2007, Tetzchner, Hesselberg og Schiørbeck 2008). Forskning som både dokumenterer barns *medvirkning* i habilitering og hva det er som gir et barn en opplevelse av å medvirke er nødvendig kunnskap for fagfeltets videreutvikling.

Forskningsprosjektet "Barn med funksjonshemning og deltakelse i egen habilitering i spesialisthelsetjenesten" har som overordnet mål å fremskaffe kunnskap om barns egne erfaringer fra medvirkning i egen habilitering. Videre er det et mål å frembringe kunnskap om hvordan profesjonsutøvere jobber for å få barn til å medvirke i beslutninger, og å finne ut av om innfallsvinkler som tidligere forskning oppfordrer til å anvende bidrar til mer medbestemmelse og delaktighet for barn som er brukere av habiliteringstjenesten. Prosjektet er et delprosjekt av et større tverrfaglig forskningsprosjekt ved Høgskolen i Oslo som heter "Snakk med oss!" Profesjonsutøvelse og barns deltakelse.

Deltakerens ansvar: Stille til avtalte tidspunkt, og å gi tilbakemelding hvis det er noe hun/han lurer på eller er bekymret for.

Generelt:

- Deltakeren vil bli orientert så raskt som mulig dersom ny informasjon blir tilgjengelig som kan påvirke deltakerens villighet til å delta i studien
- Deltakeren skal opplyses om mulige beslutninger/situasjoner som gjør at deres deltakelse i studien kan bli avsluttet tidligere enn planlagt
- Eventuelle bensinutgifter/kjøregodtgjørelse i forbindelse med intervju vil bli dekket.

Kapittel B - Personvern, økonomi og forsikring

Personvern
Opplysninger som registreres er diagnose og funksjonsvurdering hentet fra journal, som vil bli skrevet ned av en av de ansatte ved habiliteringssenteret. Forskeren vil ikke be om innsyn i journal utover dette. Navn vil anonymiseres, kun alder, diagnose og funksjonsvurdering vil bli oppgitt i publikasjoner, og omskrevet slik at utsagn ikke kan spores tilbake til personen. Hvis for eksempel hun/han har dårlig erfaring fra et habiliteringssenter vil denne informasjonen ikke kunne spores tilbake til personen ved at verken alder, kjønn eller diagnose vil bli oppgitt.

Rett til innsyn og sletting av opplysninger om deg
Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Økonomi og Høgskolen i Oslo sin rolle
Studien er et doktorgradprosjekt og er en del av et større forskningsprosjekt som heter: ”Snakk med oss – Profesjonsutøvelse og barns deltakelse”, ved Høgskolen i Oslo. Studien er finansiert gjennom forskningsmidler fra Høgskolen i Oslo, og det vil ikke koste deltaker noe å være med i studien. Eventuelle kostnader vil dekkes av Høgskolen i Oslo.

Forsikring
Å være deltaker i studien innebærer ikke at det blir tatt prøver eller iverksatt tiltak som krever forsikring.

Informasjon om utfallet av studien
Forsker vil informere om publikasjoner.

Samtykke til deltakelse i studien

Jeg/vi er villig til at vårt barn får delta i studien

(Signert av foreldre/foresatte, dato)

Stedfortredende samtykke når berettiget

(Signert av nærstående, dato)

Jeg bekrefter å ha gitt informasjon om studien

(Signert, rolle i studien, dato)

Forespørsel om deltakelse i forskningsprosjektet

”Barn med funksjonshemning og deltakelse i egen habilitering i spesialisthelsetjenesten”

Bakgrunn og hensikt

Dette er et spørsmål til deg om å delta i en forskningsstudie for å innhente informasjon om hvordan profesjonsutøvere arbeider for å få barn med funksjonshemninger delaktige i egen habilitering i spesialisthelsetjenesten. Prosjektet har til hensikt å finne ut av hvordan profesjonsutøvere kan arbeide for å gi barn både innflytelse og medvirkning i beslutninger som tas om dem. Vi ønsker å utforske hvordan profesjonsutøvere arbeider til daglig, i samhandling mellom barn og hva profesjonsutøvere tenker om sitt arbeid. I studien vil også barn i alderen fra 10-15 år bli intervjuet om deres tidligere erfaringer knyttet til medvirkning i egen habilitering. Studien er et doktorgradprosjekt og er en del av et større forskningsprosjekt som heter: ”Snakk med oss – Profesjonsutøvelse og barns deltakelse”, ved Høgskolen i Oslo.

Hva innebærer studien?

Studien vil bli gjennomført ved (…), habiliteringsavdelingen. For å utforske hvordan profesjonsutøveren jobber sammen med barn i behandlings- eller utredningssituasjoner i forhold til medvirkning, vil forskeren observere fagpersoner som sier ja til å delta i studien, i deres arbeide med 3-5 barn. Deretter vil fagpersonene gjennom samtaler og kollegamøter diskutere og reflektere rundt utfordringer ved å legge til rette for medvirkning for barn, både med og uten innspill fra forsker. Dette vil innebære to møter per semester, over en periode på to år. Mellom hvert møte kan fagpersonene bli bedt om å skrive ned erfaringer de gjør i sitt arbeid. Samtale i kollegamøtene vil bli tatt opp på båndopptaker, og det vil bli ført notater av forskeren. Det vil også bli gjennomført samtale og ett intervju med gruppeleder og avdelingsleder. Deltakelse ved habiliteringssenteret vil strekkes seg over en periode på fire semestre, med oppstart høsten 2010. Se for øvrig kapittel A.

Mulige fordeler og ulemper

Ved å delta i denne studien blir profesjonsutøvere selv gitt mulighet til å reflektere og diskutere ulike måter å arbeide på for å legge til rette for barns medvirkning i egen habilitering i samarbeid med forsker. I tillegg vil deltakerne få mulighet til å diskutere de funn som forskeren innhenter i løpet av sin deltakelse ved avdelingen. Både hva som skjer i praksis, samtaler og refleksjon vil bidra til utvikling av nye arbeidsformer. For å kunne danne et helhetlig bilde av barns deltakelse i egen habiliteringsprosess, er både informasjon sett fra profesjonsutøverens side og informasjon sett fra barns side viktig. Profesjonsutøvere kan ha betenkeligheter i forhold til det å ha en forsker tilstede under sitt arbeid, men denne innsamlingsteknikken vil gi en bredde i materialet som inkluderer konkrete beskrivelser av situasjoner sett fra en ikke-profesjonsutøvers side, som vil være viktig for samtalene og diskusjonene profesjonsutøverne vil ta del i. For de ansatte vil deltakelse i prosjektet ta av deres arbeidstid. For senteret som helhet vil dette gi en mulighet for å bidra innen fagfeltet, samt forbedre praksis ut fra egne premisser.

Hva skjer med informasjonen fra deg?

Informasjonen fra deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og eller andre direkte gjenkjennende opplysninger. Profesjon og yrkeserfaring vil det være ønskelig at vi får oppgitt. Informasjonen som vil fremkomme fra deg som

profesjonsutøver vil omhandle profesjonsutøvelse, og tanker du dere har rundt dette. Materialet vil oppbevares innelåst i et arkiv, og vil bli anonymisert ved publikasjon.

For andre ansatte og eventuelt foreldre og barn som kjenner deg og ulike situasjoner dere har samhandlet i, vil det være mulig å kjenne deg igjen. Uttalelser vil bli anonymisert hvor verken kjønn eller alder vil bli oppgitt. Utover dette vil andre ikke kunne spore opp hvem det er snakk om eller som uttaler seg.

Frivillig deltakelse
Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte Wenche Bekken på telefon
22 45 25 18/00 00 00 00.

Samtykkeerklæring følger etter kapittel B.

Kapittel A- utdypende forklaring av hva studien innebærer

Kriterier for deltakelse:
Være ansatt ved habiliteringssenteret, og å ønske å samarbeide for å få prosjektet gjennomført.

Bakgrunn for studien:
Statens helsetilsyn konkluderer i sin rapport "Ikke likeverdig habiliteringstjenester til barn" (2007), at det er brudd på retten til informasjon og medvirkning. Forskning gjort i Sverige (Bolin et.al 2003) viser at barn med funksjonshemning i liten grad kan forklare hvorfor de gjør som de gjør i en habiliteringsprosess, bare hva de gjør. Vi vet fra annen forskning og dokumentasjonsarbeid gjort i skolen at barn med nedsatt funksjonsevne opplever det meningsfullt å være deltakende, men at det varierer hvor deltakende de er i planleggingsprosesser (Asbjørnslett 2005, Assistanse 2009, NHF Oslo 2007, Tetzchner, Hesselberg og Schiørbeck 2008). Forskning som både dokumenterer barns *medvirkning* i habilitering og hva det er som gir et barn en opplevelse av å medvirke er nødvendig kunnskap for fagfeltets videreutvikling. Forskningsprosjektet "Barn med funksjonshemning og deltakelse i egen habilitering i spesialisthelsetjenesten" har som overordnet mål å fremskaffe kunnskap om barns egne erfaringer fra medvirkning i egen habilitering. Videre er det et mål å frembringe kunnskap om hvordan profesjonsutøvere jobber for å få barn til å medvirke i beslutninger, og å finne ut av om innfallsvinkler som tidligere forskning oppfordrer til å anvende bidrar til mer medbestemmelse og delaktighet for barn som er brukere av habiliteringstjenesten.

Tidsskjema – hva skjer og når skjer det?
Fra og med høsten 2010 vil det bli gjennomført deltakende observasjon på habiliteringsavdelingen, hvor de aktuelle profesjonsutøverne vil bli fulgt av en forsker i 3-5 konsultasjoner med barn og deres foreldre. Fra og med våren 2011 vil samtaler og kollegasamtaler starte opp og vare over en periode på 2-3 semestre, avhengig behov. Dette vil som nevnt ovenfor dreie seg om to møter hvert semester med en varighet på 1,5 timer. Intervjuene med ledere vil vare fra 1-1,5 timer. Framdriftsplanen vil bli lagt frem og utviklet i samarbeid med profesjonsutøverne som deltar.

Deltakernes er ansvar:
Bidra til at informasjon blir gitt ved å samarbeide om det opplegget som er lagt for innhenting av informasjon.

For ledere:

- Stille til intervju/samtale
- Informere avdelingens ansatte om forskningsprosjektet, og at dette er et prosjekt avdelingen ønsker å få gjennomført. I tillegg til forskers deltakelse i konsultasjoner vil innebære at forsker er til stede på møter.

Kapittel B - Personvern, økonomi og forsikring

Personvern

Alle opplysninger vil bli behandlet uten navn eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste.

Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg.

Økonomi og Høgskolen i Oslo sin rolle
Dette er et doktorgradsprosjekt finansiert av Høgskolen i Oslo. Institusjonen anses ikke for å ha spesielle økonomiske interesser i habiliteringsavdelingen.

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Samtykke til deltakelse i studien

Jeg er villig til å delta i studien

(Signert av prosjektdeltaker, dato)

Stedfortredende samtykke når berettiget, enten i tillegg til personen selv eller istedenfor

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(Signert av nærstående, dato)

Jeg bekrefter å ha gitt informasjon om studien

(Signert, rolle i studien, dato)

Forespørsel om deltakelse i forskningsprosjektet

"Barn med funksjonshemning og deltakelse i egen habilitering i spesialisthelsetjenesten"

Bakgrunn og hensikt
(…) barnehabiliteringssenter vil i løpet av en periode på tre år være med i et forskningsprosjekt med Høgskolen i Oslo. Forskningsprosjektet har som mål å få kunnskap om barns erfaringer fra deltakelse i egen habilitering. Videre er det et mål å få kunnskap om hvordan profesjonsutøvere jobber for å få barn til å medvirke i beslutninger, slik at nye måter å jobbe på for å sikre barns medvirkning i beslutningsprosesser kan strykes. Dette er en forespørsel til dere som foreldre/foresatte og barn som vil være brukere av barnehabiliteringssenter i løpet av forskningsperioden om å samtykke i at en forsker er tilstede og observerer fagpersoner i utrednings- eller behandlingssituasjoner av barnet deres. Studien ønsker å bidra til at barns rett til å bli hørt blir styrket. Studien er et doktorgradprosjekt og er en del av et større forskningsprosjekt som heter: "Snakk med oss – Profesjonsutøvelse og barns deltakelse", ved Høgskolen i Oslo.

Hva innebærer studien?
For dere vil et samtykke innebære at en forsker vil være tilstede og se hva som skjer i behandlingssituasjoner. Fokuset vil ligge på den/de ansatte, men det kan bli behov for å stille noen oppklarende spørsmål underveis. Hva som skjer i selve utredningssituasjonen som kan eksemplifisere barns deltakelse i beslutninger, vil bli brukt i forskningspublikasjoner. Hvis du/dere ikke ønsker å ha forskeren/undertegnede tilstede, vil konsultasjonen forløpe som vanlig med behandler. Kun underskrevet samtykke fra barn og/eller foreldre gir forsker mulighet for å være til stede i behandlingssituasjon med dere.

Mulige fordeler og ulemper
Det anses ikke å være en ulempe for dere å ha en forsker til stede, utover at det er en ekstra person tilstede. Ved å tillate deltakelse vil dere bidra til utforskning av hva som er viktig for utvikling av barns rettigheter og medbestemmelse generelt, og for medvirkning for barn med nedsatt funksjonsevne spesielt.

Hva skjer med informasjonen om deg/dere
Det vil ikke være aktuelt å innhente informasjon om barnet verken fra journaler eller registre. Det som skjer mellom behandler og barnet/foreldrene er det som vil dokumenteres. Informasjonen som registreres om deg/dere skal brukes slik det er nevnt ovenfor og som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger.

For deg/dere og behandler som er til stede vil det ved en fortelling av hva som skjedde i selve behandlingssituasjonen, være mulig å kjenne igjen situasjon og personer. For andre som ikke kjenner til dere det være vanskelig å se hvem dette gjelder siden navn og bosted ikke oppgis. Og det vil kun være eksempler som illustrer måter å jobbe med barn på som skal bidra til økt deltakelse fra barnets side vil bli brukt.

Frivillig deltakelse
Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få konsekvenser for barnets videre behandling. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker barnets øvrige behandling. Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte Wenche Bekken på telefon 22 45 25 18/00 00 00 00.

Ytterligere informasjon om studien finnes i kapittel *A* – *utdypende forklaring av hva studien innebærer.*
Ytterligere informasjon om personvern finnes i kapittel B – *Personvern*

Samtykkeerklæring følger etter kapittel B.

Kapittel A- utdypende forklaring av hva studien innebærer

Bakgrunnsinformasjon om studien:
Barn er brukere på lik linje med voksne innen habilitering, og skal ha en medvirkende rolle i egen habiliteringsprosess. Barneloven slår fast at barn helt ned til syv år har rett til medbestemmelse i beslutninger som gjelder dem.
Statens helsetilsyn konkluderer i sin rapport "Ikke likeverdig habiliteringstjenester til barn" (2007), at det er brudd på retten til informasjon og medvirkning. Forskning gjort i Sverige (Bolin et.al 2003) viser at barn med funksjonshemning i liten grad kan forklare hvorfor de gjør som de gjør i en habiliteringsprosess, bare hva de gjør. Vi vet fra annen forskning og dokumentasjonsarbeid gjort i skolen at barn med nedsatt funksjonsevne opplever det meningsfullt å være deltakende, men at det varierer hvor deltakende de er i planleggingsprosesser (Asbjørnslett 2005, Assistanse 2009, NHF Oslo 2007, Tetzchner, Hesselberg og Schiørbeck 2008). Forskning som både dokumenterer barns *medvirkning* i habilitering og hva det er som gir et barn en opplevelse av å medvirke er nødvendig kunnskap for fagfeltets videreutvikling.
Forskningsprosjektet "Barn med funksjonshemning og deltakelse i egen habilitering i spesialisthelsetjenesten" har som overordnet mål å fremskaffe kunnskap om barns egne erfaringer fra medvirkning i egen habilitering. Videre er det et mål å frembringe kunnskap om hvordan profesjonsutøvere jobber for å få barn til å medvirke i beslutninger, og å finne ut av om innfallsvinkler som tidligere forskning oppfordrer til å anvende bidrar til mer medbestemmelse og delaktighet for barn som er brukere av habiliteringstjenesten.

Tidsbruk
Deltakelse i studien innebærer ikke tidsbruk utover den fastsatte konsultasjonen med senterets ansatte.

Kapittel B - Personvern

Personvern
Opplysninger som fremkommer i behandlingssituasjonen om deg vil bli anonymisert i form av at den ikke vil knyttes til en enkelt person. Notater fra behandlingen vil bli oppbevart i et innelåst arkivskap.

Rett til innsyn og sletting av opplysninger
Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om ditt barn. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede observasjonsnotater, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Studien er et doktorgradsprosjekt som er finansiert gjennom forskningsmidler fra Høgskolen i Oslo. Prosjektet er en del av et større prosjekt "Snakk med oss – barns deltakelse og profesjonsutøvelse" som er et tverrfaglig forskningsprosjekt ved Høgskolen i Oslo.

Forsikring
Studien vil ikke utsette pasienter for tiltak eller prøver. Forsikring er derfor ikke aktuelt.

Informasjon om utfallet av studien
Alle deltakerne i studien vil få informasjon om studiens resultater, enten ved å blikontaktet direkte eller via informasjon på habiliteringssenterets nettside.

Samtykke til deltakelse i studien

Jeg/vi er villig til at en forsker er til stede under utrednings- eller behandlingssituasjon

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(Signert av prosjektdeltaker(forledre/foresatte), dato)

Stedfortredende samtykke når berettiget, enten i tillegg til personen selv eller istedenfor

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(Signert av nærstående, dato)

Jeg bekrefter å ha gitt informasjon om studien

(Signert, rolle i studien, dato)